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Hope and the meaning of life in adolescent cancer patients – a phenomenological study

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Abstract

The aim of this study was to explore how adolescents diagnosed with cancer find meaning in their lives and what factors facilitated their resilience in coping with treatment and the fear of death. Treatment of cancer results not only in loss of hair and body parts, but also of self-control and dignity and when this occurs during adolescence, a stage of life during which the child evolves cognitively and morally and when self-identity is evolving, what do adolescents cling to in the midst of being treated for cancer and the consequent experience of uncertainty and loss? Facilitated by participant narratives and Interpretive Description methodology, this study explores the theme of spirituality and hope as core enablers of resilience in adolescents undergoing cancer therapy, and how the diagnosis of cancer frames their meaning of life. Thirteen adolescent patients were interviewed and, even though buffeted by illness, all expressed a will to live and a hope to get better. Although there are many dimensions that contribute to resiliency this study focused primarily on the domains of hope and spirituality. Five domains were identified that highlighted both internal strengths and external supports that play important roles in the resilience of youth. Themes that emerged were redefined relationships with parents and friends, threatened social networks and halted normal adolescent development. In addition, a sense of spirituality and optimism emerged as themes. It is from our patients and their shared insights from their lives, illness and suffering that we as clinicians learn. This study helps to better understand, in adolescents, what illness takes away and how as health care providers we can holistically respond.

"The most beautiful people we have known
are those who have known defeat,
known suffering, known struggle, known loss
and have found their way out of the depths.
These persons have an appreciation,
a sensitivity, and an understanding of life
that fills them with compassion, gentleness,
and a deep loving concern.
Beautiful people do not just happen."

Elisabeth Kubler-Ross

Chapter 1: Structuring the Study

This research project has evolved out of my practice as a consultant paediatric oncologist. Throughout my career evidence-based medicine has predominated and randomized clinical trials are the research modality I know best. As clinician scientists we are induced to believe that reasoning can only be cognitive and evidence-based, even though as paediatricians we recognize the importance of the social, emotional and developmental domains. Exploring these dimensions has always been pushed into the background; in the busyness of day-to-day clinical practice there is never enough time to really explore these kinds of issues in the depth that I believe they deserve. There is now starting to be some room again in medicine for evoking a more humanistic approach, facilitated by narratives and newer methodologies to help explore these qualitative dimensions in depth.

This study explores how adolescents faced with a life threatening illness, more specifically cancer; find meaning in their lives and what factors facilitate their resilience in coping with treatment and the fear of death. Although there are many dimensions that contribute to resiliency I wanted to focus primarily on the domains of hope and spirituality. My adolescent patients, even though buffeted by illness, express a will to live and a hope to get better. It is this inner strength that has motivated this study with the objective to learn more about their hope and spirituality. These are both poorly described in the literature and a topic not often discussed in clinical care. With a better understanding the objective would be to be able to better facilitate resilience.

The transition from childhood to adulthood is the period known as adolescence [Oxford Dictionary 1996]. This is a period of transition characterized by rapid physical, emotional and social changes: a time of becoming, of wanting to belong and of social development. "Who am I" and "how do I fit in" are key components to the young person's psyche as he or she transitions into adulthood. As Justice Abella has commented: "maturity" is an imprecise standard, given "the inherent imprecision of childhood and adolescent development." Reasons: *A.C. Vs. Manitoba (Director of Child and Family Services*), (2009) S.C.J. No. 30. Adolescents pose unique challenges in clinical care. They are evolving and gaining capacity, and while they are no longer children they are not yet adults. Their identities are evolving and chronic illness

unfairly impacts these young people at a time when this exploration of identity is so forceful.

Illness, especially one that specifically carries a poor prognosis, brings fear and uncertainty, and it is this fear and uncertainty that threatens the healthy development of these young people. How do they find the capacity to resist stress and bounce back in the face of adversity? The literature speaks of protective factors that buffer these children (Resnick, 2000). Both internal strengths and external supports play important roles in the "bouncing back" or in the resilience of youth and all its different components.

Clinicians treating children and adolescents diagnosed with cancer understand that resilience and optimism are important dimensions in the care of these patients. As Margaret Mohrmann (2007, p19) comments these are "children and parents cast unwillingly as patients in medicine's theatre" and it is from their lives and suffering that we learn. We learn to treat not just the physical symptoms but that there is another facet to devastating illness and suffering that needs to be addressed. How do we restore what illness takes away?

Karl Menninger highlighted the importance of 'hope' as early as 1959, and it is now recognized that hope has the capacity to generate attitudes consistent with better treatment outcomes (1959). Hope and resilience (Penson, 2007) as constructs have been described as helping in the face of adversity. Mainstream medicine and social sciences have neglected the inquiry into both hope and spirituality despite the reality as Viktor Frankl states that "difficult situations are what give man the opportunity to grow spiritually beyond himself" (1946, pp113-114).

In a support document for provision of social services in Scotland, the Institute for Research and Innovation in Social Services [Insights January 2013] commented that the definition of spirituality is "problematic…and an evolving concept" but that this dimension in health care focuses on hope and a sense of meaning of life. The World Health Organization also speaks to the value of "spiritual elements" in health care; how this is realized in treating patients and more specifically, adolescents remains unknown. For many the construct of spirituality remains 'problematic' as it remains a nebulous concept that has a moral and or religious character rather than a social or scientific one. Stripped of its religious associations, it may simply be 'resilience'. The 2013 International Conference on Improving the Spiritual Dimension of Whole Person Care in Geneva defined spirituality as a " dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence: and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices".

Spirituality is triggered by the ultimate existential questions. These are the questions that lie at the heart of our being and our very existence and not unique to the adolescent period. Everybody has some sense of what their own answers are to these ultimate existential questions. Every individual has their own personal set of core beliefs, values, and understanding of the purpose and meaning of their life. What ***are*** the core questions of ultimate concern? The

questions we all find ourselves asking: how did it begin, where do I come from? Why do I exist? Why am I here, what is the point and purpose of my life? Where do I find hope, joy, justice, healing? These questions for patients may include why is there pain, suffering, death? How can I and how should I respond to these realities? A life threatening illness may prompt these ultimate existential questions with questions about what provides the life force, what brings endings and new beginnings? How is it that life on earth is consistently maintained and also constantly changing and evolving?

Everybody has some sense of what their own answers are to the ultimate existential questions. Every individual has their own personal set of core beliefs, values, and understanding of the purpose and meaning of their life. This is a personal faith and a general sense of being a *spiritual* person rather than a *religious* person. I have used the term ‘personal faith’ here as many postmodern sceptics struggle with the touchy-feely language and practices of modern day 'spirituality' and dislike the term ‘religion’. Faith remains a trigger word for many but it may better describe what is at the heart of an individual’s response to the ultimate existential questions, as that response could be very spiritual, or traditionally religious, or simply very rational and logical. In the thesis I will use personal faith and spirituality interchangeably. What I hope in my thesis is to defend that spirituality adds dimensions to resiliency that are important dimensions in the care of adolescents with cancer.

Treatment of cancer may result not only in loss of hair and body parts, but also of self-control and dignity. So what do adolescents cling to in the midst of being treated for cancer and the consequent experience of uncertainty and loss? Consideration of hope in adolescents is complicated by the aforementioned reality that this is a stage of life during which the child evolves cognitively and morally and when self-identity is evolving. Faced with a cancer diagnosis adults experience the same loss but they, unlike adolescents, have already experienced a past. This brings experiences and life events that adults are able to reflect on, experiences that they can recount gratitude for the life lived and a sorrow for the loss. Adolescents faced with death, have relationships with parents redefined and relationships with friends threatened, stripped social networks and arrested normal development, so how do adolescents with cancer find their meaning, their spirituality and their optimism?

This study will explore the theme of spirituality and hope as core enablers of resilience in adolescents undergoing cancer therapy, and how the diagnosis of cancer frames their meaning of life.

My thesis will be divided into the following structure:

Chapter 2: Exploring the landscape: Literature review

The landscape of adolescence, cancer, resilience and more specifically hope and spirituality is vast and, to fully appreciate the depth and colour of this landscape, different lenses are required. The purpose of the literature review was to examine the spirituality literature in adolescents with cancer and provide this in the context of adolescent development. An understanding of

developmental theory and the impact of stress on the evolving adolescent are essential in order to provide a context for insight into their spiritual development and how they make sense of life. This chapter describes how the literature informs our understanding of the topic and what new insights this thesis may add. The review of the literature became an iterative process and was additionally informed by the concepts discussed by the participants themselves and these concepts further elucidated in later chapters.

Chapter 3: Constructing the study

This chapter describes the aims and design of the study. It details the methods employed, together with a critical evaluation of the methodology, outlines the analytical process and explores the ethical implications arising from the research.

Chapter 4: Analysing the narratives

In this chapter the narratives shared by the adolescent participants will be described and emergent themes identified and explored and deeper exploration in the literature of these emergent themes, along with personal reflections and interpretation by the author.

Chapter 5: Conclusions

This chapter will reflect on the whole study, the lessons learned, personal reflection and how these might impact clinical care and potentially alter practice. The limitations of this study and where this research may lead in the future will be discussed in this chapter.

Hope is not rational.
It is emotional, energetic.
A facet of love.

Thomas Moore-Jungian

Chapter 2: Exploring the Landscape

Literature Review

In this chapter I will outline the research that exists regarding hope in adolescents and the shortcomings of that literature as it pertains to my study. I will try to define some of the principal terms used when addressing hope in adolescents, attempt to describe adolescence more fully, explore resilience and delve a little into the spirituality literature. I will illustrate the gaps that exist and outline the need for this study. As my study evolved themes emerged from the interviews that my initial literature review had not considered. Themes emerged from the interviews that prompted wider literature review and therefore the literature review became an iterative process. This process is born out in further themes being explored and described in later chapters. A schematic representation of the literature review and how the research itself informed the review is shown diagrammatically. (Appendix 1) Literature around these themes is reviewed in Chapters 4 and 5 as they naturally emerged.

Reviewing the topic of hope in adolescents has been an interesting and diverse journey through the literature. The search engines used were Pub Med, Web of Knowledge / Web of Science and OvidSP (Medline). Attempts to better define spirituality, hope and meaning of life have been described in theological, nursing and psychological literature. so in addition, Cumulative Index for Nursing and Allied Literature (CINAHL), and Social Science Citation Index (SSCI) were explored. The University of Alberta has a Hope Studies Central (www.hope-lit.ualberta.ca) and claims to be the only research centre in the world devoted to studying hope in humans. As a service they provide a hope-lit database that served as a useful and very comprehensive reference resource. In addition the director of the Hope Studies Centre was a useful source of advice and guidance.

The main concepts that I searched in the databases were *hope, spirituality*, and *meaning for life*, *resilience, self-identity and positive adaptation.* Additional key terms used were, *oncology, teenagers, adolescents, children, risk and palliation*. Certain terms were exploded and Boolean combinations further defined the search. Review of the literature included English language publications from 1980 to 2016 and was conducted from 2009 to 2015. Although the focus of the research was adolescent patients the search did not restrict to this age group and adult literature was included. Numerous publications were identified in six main concepts (Table 1). This highlighted the diversity of the topic, the lack of definition and the Western orientation of the literature. In order to remain current, literature alerts were in place to highlight

new publications and key researchers in the area were scanned and unpublished data reviewed.

Concepts searched	Authors	Frequency
Spirituality	Mc Sherry (4), Hendricks-Furguson(1), Woodgate(4), Chochinov(1) , Cook(1), Cotton(1), Haase(5), Muellen(1), Oldnall(1), Tanyi(1)	20
Hope	Cantrell(1), Dutcher(1). Groopman(1), Herth(2), Hinds(5), Juvakka(1), Jevne(2), Kodish(2), Moadel(1), Nekolaichuk(2), Nowatny(1), Penson(1), Ruddick(1), Rustoen(1)	21
Religion	Fowler(2), Kaufmann(2), Roehlkepartain(book)	4+
Developmental Theory	Blustein(1), Fowler(2), Hart(1), Konopka(1), Lau(1), Neuman(1), Oser(1), Piaget(2), Schnell(1), Siegler(1), Singleton(1), Zimmerman(1)	14
Adolescent Cancer/illness/pain suffering	Bleye(1), Haase(5), Juvakka(1), Linaby(1), Woodgate(4)Bury (1), Kane (1), Kuttner(1)	15
Resilience	Cicchetti(1), Coleman(1), Ginsberg(1), Kumpfer(1), Luthar(1), Masten(1), Wagnild(1)	7

Table 1: Publications in Literature Review

The health care literature that was searched highlighted papers that emerged mostly out of the discipline of nursing and spanned the last four decades. The 1980's saw burgeoning research in this area and the start of exploration into the concept of hope in teenagers and young adults. Over the last few decades a small group of prominent researchers have dominated the health care literature in the field, namely Hinds (1988, 2000, 2004), Jevne (2007, 1993), Woodgate (2002, 2005, 2006, 2000), Haase (2004, 1994, 2007, 1992) and McSherry (2004, 2006, 2007, 2012). Many of these authors describe normal adolescents, those without illness, adults with cancer or adults with chronic illness. In this body of literature some authors also described hope and spirituality in the arena of palliation and end-of-life care (Chochinov and Cann, 2005). Most recently, in 2009, a paper from Finland (Juvakka, 2009) was published using hermeneutic philosophy to describe hope in adolescents with cancer but the study included only 6 participants and a very heterogeneous sample.

I wanted to focus my research more on, what I call the "art of medicine" and not the science and to focus on psychological concepts. Panda (2006), in The Mens Sana Monographs concludes that Medicine is both an art and a science and because in medicine we are treating human beings with a body, a mind and soul and so the art of caring is as intertwined with the science and the technology. To fully explore the art of medicine literature I used PsychInfo to further expand the literature search into the psychology literature. In addition, psychiatric, rehabilitative (Russinova, 1999) (Kautz, 2008) and adult oncology literature (Jevne, 1993) (Wong, Wylie 1996, 1996) (McSherry, 2006) were all explored. These papers all helped to expand the topics of hope and spirituality but highlighted how little research is specific to adolescents. Although this literature helped to establish themes to further expand the search, it also illustrated the importance of exploring hope and spirituality in the context of the developing adolescent. Hope and its impact on health outcomes have been reported in the literature. In these papers different outcome measures, such as

quality of life (Rusteon, 1995), spirituality (Haase, 1992) and mental health (Nunn, 1996) were addressed but not in teenagers or in children. Hope and spirituality as 'independent' or 'dependent' variables on outcome are difficult to determine and one cannot determine if it is it a cause or an outcome of a process? The relationship is much more complex and it is this processes by which spiritually both develops and, in turn, affects, other aspects of the child's world view that my research seeks to explore.

Hope

There have been a variety of attempts in the literature to define and quantify hope. These include quantitative methods where the constructs of hope and spirituality were measured (Moadel, 1999), descriptive frameworks and measurement scales (Nowotny, 1989). The Nowotny Hope Scale, the Herth Hope Index (Herth, 1991) and the Miller Hope Scale (Miller, 1988) are the most described and have all been validated in adult patients. While these are helpful, I believe these would require validation before their value within paediatrics can be assessed since children are not just little adults. Since the validity, reliability and universality of these frameworks or scales have not been assessed, they are not used routinely in paediatric care.

Not only is children's hope not formally assessed but also in clinical practice this dimension of care is not considered as part of the medical plan (Haase, 2007) (Herth, 1992, 1991). Hope remains a construct that current scientific-based approaches are not able to fully address. This may illustrate a basic epistemological view or simply that the concept of hope is a difficult one to define or that it remains nebulous? It may also be that the construct of hope encompasses many other concepts; optimism, resilience, self-efficacy, which might be better analysed individually. Other methodologies different to traditional quantitative ones need to be developed and researched fully to further assess these concepts. The scientific literature comments on the fact that hope is positively linked to health (Nekolaichuk, 1996, 1999) and to treatment outcomes. It is for this reason that including discussions on hope in patient interactions is important. How to engage in these discussions and what patients want to discuss needs deeper analysis. Haase (2004) comments on methodology that research in oncology should shift away from the pure quantitative studies and to focus on qualitative concepts "such as hope, spirituality… and the adjustment to the cancer experience". Perhaps the time is here to not just have sole focus on research on medical treatment of cancer but to focus also on the patient's emotional response to their situation.

As a clinician, it is important to not make assumptions about patients but encourage them to share how they experience cancer personally and what these constructs mean to them individually. Qualitative methodologies, particularly phenomenological and ethnographic approaches, allow the researcher to explore the lived experience. Research on the themes of hope and spirituality may provide insights on how to empower hope, provide strategies for coping and ultimately improve well-being. An equally important concept to explore with patients is the one of false hope and to guide health care providers on how to avoid this deception. Ruddick (1999) talks about the deception arising from giving false hope and the harm that may be caused by

loss of hope. She believes that the enabling of hope has a “distinct place among the basic ethical principles”. How adolescents wish to receive information and how patients make sense of their illness may provide insight on how to deliver news and improve communication.

Spirituality

The concept of spirituality is difficult to define since the concept is vague and very individual. How do we define an individual in the spiritual context? Charles Taylor (1989) describes the modern identity in which he describes a moral framework within which contemporary moral values exist. He articulates this moral framework in terms of three axes.

The first axis refers to “beliefs about the value of human life, how people should be treated, the respect we afford to human life and the moral obligations these beliefs demand from us”. The second refers to beliefs about the “kind of life that is worth living, beliefs that permeate our choices and actions in our day-to-day existence”. The third axis refers to the dignity we afford ourselves and others based on how we understand our role in society and usefulness in society. These three axes frame the individual worldview and their belief and value structure. For some individuals the notion of spirituality acknowledges a Divine presence and for others it has a more secular definition, a concept of inner life and a focus on the self.

In a report on spirituality and ageing by Iriss, a charitable company with a mission to promote Scotland’s social services, authors Mowat and O’Neill (2013) comment that spirituality can be thought of in different ways and describe four distinct concepts. The first concept is that spirituality can be considered as part of a religious belief or a value structure in relation to God. The second concept is a secular one, where the focus is on nurturing of the human fabric. Interestingly, they comment on spirituality as a “metaphor for absence” and more particularly in health care as the absence of a specific type of care when one is ill. The third definition is one where spirituality is seen as a “search for meaning”, either through a relationship with God or with others. Finally, the fourth way is as a value and meanings structure guiding how people live. Furman (2004) defines spirituality in very concrete ways as being theistic, atheistic or non-theistic. This latter definition still links spirituality to religion. Over the last few years the notion that they are separate entities has been accepted; Nolan (2011) suggests that spirituality has become “uncoupled” from religion.

McSherry and Smith (2012) suggest that “Spirituality is universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity.”

A consensus report prepared by the National Institute for Healthcare Research in the United States, not to be confused with the National Institute of Health Research, defined spirituality as “behaviours, cognition and emotions that arise

as part of an individual's search for connection with a Devine being, a higher power or an ultimate truth" (George, 2000). In contrast religion is given a more structured, societal phenomenon and aligned with more ritualistic and formal approaches in the search for spirituality.

There is a lack of clarity in the literature as to what constitutes spirituality however; common themes emerge on the concept. These are concepts and constructs that go beyond physiological and rational understanding. Spirituality is a more subjective construct whereas religion is more structured and associated with an institution. It appears that spirituality is a generic term being used for each individual embraces as their frame for understanding life; their own lives, death and suffering.

Resilience

Resilience is a term used widely in the literature and open to many interpretations. The key conceptual constructs of this theory explain a positive adaptation in the face of adverse conditions and traumatic events. Resilience theory emphasizes positive responses and dynamic mechanisms in the face of a difficult situation mostly attributed to childhood or adolescence. It may be influenced by personality and tends to change over the life span (Coleman, 2007). A consistent theme in the growing body of literature (Luthar, 2000) (Cicchetti, 2006) (Masten, 2006) (Kumpfer, 2006) is the importance of relationships and the feeling of connectedness. Connections with parents, family and friends, mentors and with social networks are important. School, peers and adults, with whom children have authentic relationships, play important roles in fostering this sense of connectedness and belonging. How illness impacts resilience is addressed in the disability literature (Coleman and Hagell, 2007) that suggest that physical and mental challenges pose risks and a potential for isolation and poor coping. Missing in the literature, however, is the impact a diagnosis of cancer has on resilience.

Spirituality is also discussed in the literature as enhancing resilience (Luthar, 1991). This spirituality is defined as a sense of being connected with the greater forces in the universe, connecting with the "Wonders and the mystery of the Universe" leading to connectedness, purpose and contribution. The literature (Roehlkepartain, 2006) distinctly separates these concepts from religion, which he/she defines as doctrines with rituals expressed by a group of individuals.

Equally, optimism and having a sense of purpose in life are important themes in the resilience literature (Matthews, 2009). Having a sense of awe and of the endless possibilities available to youth feeds self-esteem. Self-esteem is seen as an essential internal strength and important in fostering resilience.

Different models of resilience have been developed in an attempt to understand coping and recovery and to help in developing appropriate interventions to support adolescents in times of risk (Zimmerman, 2005). In this article the author describes different models; compensatory, protective and challenge ones. Various other models and scales have been developed, one such tool is a psychometric evaluation of resilience (Wagnild and Young, 1993) which is

helpful in an attempt to understand the different responses adolescents have in times of stress and when and how to intervene with risk reduction strategies. Kenneth Ginsburg has popularized the 7 C's of resilience. These include confidence, competence, connection, character, contribution, control and, last but not least, coping. I think this helps us frame the elements of resilience but ignores the individuality and diverse factors influencing the lives of youth.

Resilience, however, differs from the traditional concept of risk protection in that it focuses on individual responses to comparable experiences. Therefore, it is important to focus on individual responses and to reflect on the causal processes much as dissecting the elements producing resilience as a general quality in youth. Research methodologies that are able to truly highlight these individual differences and similarities need to be employed. Interpretive Description and constructivist grounded theory are but two examples of such approaches.

Meaning of Life

Individuals overcoming adversity and succeeding have been described for centuries and in many cultures. Universal protective factors seem to exist and are universal to adolescents too. Gisela Konopka (1973) described fundamental requirements for adolescents to thrive. Like most authors on resilience and risk (Poveda, 1992) speaks of the need for adolescents to belong, to participate in decision-making and to interact with a peer and social groups. They need to develop skills in self-reflection and to discover who they are. This discovery may be through risk taking, self-expression or experimentation. Through this journey, adolescents formulate their own values and become accountable for their actions. Not acquiring these fundamentals due to abuse or illness may lead to increased risk-taking behaviour and this is well described in the literature. However, literature specifically pertaining to the adolescent cancer patient and the impact of the isolation of illness on acquiring these fundamentals is very sparse.

The literature supports an increased interest in the need for reflection, self-discovery and spirituality. However there is no consensus on the definition of the concept of spirituality and meaning of life in the medical literature (McSherry, 2006) (Tanyi, 2007) (Muellen, 2010) . Spirituality is a primal component of being a human being. It is multidimensional and subjective. Spirituality and religion are often used interchangeably, but even in the literature the difference between the two is not clearly delineated. The most accepted definitions conceptualize spirituality as the search for the meaning of life and characterizes religion as a more organized entity with rituals and practices (Cook, 2006). It would be simplistic to think spirituality had one universal definition, and the literature supports this. In fact, 13 conceptual components have been identified from the review of the literature. Most frequent, these are 'relatedness', 'transcendence', 'meaning', 'purpose', 'wholeness' and 'consciousness'. A more recent definition of spirituality is "giving expression to the being that is in us" (Cook, 2006), perhaps best described as the development of an entity that emerges in pursuit of meaning, purpose, connectedness and contribution.

Hendricks and Ferguson (2008) describes how this search for meaning is part of normal development in children. Erikson and Piaget describe the cognitive and emotional development of children, and Kohlberg the moral development. Fowler, however, believes spirituality is an integral part of normal adolescent development alongside social, emotional and moral development. This is further explored later in this chapter.

Cotton et al. (2006) describe how in patients with HIV/AIDS, spirituality and religion were central issues when dealing with a chronic life threatening illness. Cotton failed to define the difference between these concepts but in the philosophical literature, which includes the works of Frankl (1946), Nietzsche (Mencken, 2008), and Skinner (Mencken, 2008), they all clearly describe spirituality as non-denominational and describe the sense of being and the awe within us. What spirituality means to adolescents with cancer has not been defined. In this study I hope to explore conceptually what the important elements are in the cancer experience of these young people.

Developmental Theory

Adolescence is a unique developmental stage requiring considerable adjustment. Coleman suggests that young people share common characteristics during these years of transition, including a feeling of anticipation for the future but with regret for their lost childhood; anxiety for the future; not feeling sure of their status or role in society; and experiencing relationship adjustments (2007). As the child grows physically in early childhood, concurrently psychosocial and moral traits develop (Siegler, 2006). As children develop physically and hormonally the period of adolescence is encountered. Younger and older adolescents display different developmental levels, following their own trajectories (Singleton, 2007). This is an important aspect to consider when including a widely diverse group of teenagers in a study. The exploration of hope and spirituality in the context of the developing adolescent may be different to other human developmental phases.

Erik Erikson's theory of adolescent personality development focuses on identity formation. Unlike Freud who focused on biology and sexuality, Erikson focused on the social and cultural context and the influence on the developing self. Many theories of child development exist all from different aspects. To appreciate the different theories these are summarized in Table 2 on page 19-20. Unlike the other developmental theorists like Erikson, Piaget and Kohlberg Fowler (2004) added the dimension of faith development and described 6 distinct stages (Fowler described faith rather than religion or formal belief); his findings which have been found to be uniform across different religious beliefs but focuses more on the traditional faith rather than spirituality. The first three of his stages pertain to children and adolescents and stages 2 and 3 are particularly pertinent to this thesis. Stage 2, the Mythic-Literal Faith is characterized by an understanding of cause-and-effect and literal symbolism. God is seen as a physical person and deals fairly with all people. Fowler suggests that some adolescents get "stuck" in stage 2 and continue to believe in a higher power (God) with the ability to reward people positively. Fowler viewed his stages of development as more spiral in nature as opposed to the other developmentalists who viewed development in a more linear fashion.

Stage 3, the stage where Fowler suggests the majority of people find their "home", emerges when people begin to recognize that bad things can happen to good people. In stage 3, known as the Synthetic-Conventional Faith stage, the adolescent is able to reflect on their own thinking and analyse ideas. This stage parallels the development of the person cognitively, socially, behaviourally and emotionally, resulting in a search for identity, which may or may not include the search for a Divine being. Fundamentally this stage focuses on interpersonal relationships and the relationship with a Divine presence is one that affirms the adolescent's self-identity.

According to Piaget, this developmental stage sees the child becoming more analytical and abstract in his or her thought processes. Erikson describes how, in this phase, peers become important and faith in one's self begins to emerge. Fowler (2004) weaves in the ability to reflect on symbols: God as a companion and belief as a system for example formal religion, prayer or ritual. In this phase the mystery and complexity of their own evolving identity becomes important and how they view their spirituality becomes wrapped up in this belief system. Neuman (2011) provides an interesting study exploring children's faith using Fowler's stages of Faith. Neuman (2011) argues that the understanding of child development in conjunction with an understanding of Fowlers stages will facilitate competency in providing holistic care for any age group of child.

This evolving faith identity may be expressed by conforming to ritual or mainstream religion, and may also include an identity different to that of the child's family. It would be unusual for an adolescent to move onto stage 4, the Individualistic-Reflective stage, in which people become more able to reflect on their own belief and separate it from ritual and symbolism (Fowler, 1981). In this stage youth have the ability to reflect critically on values, beliefs and commitments. Here they develop a self-identity capable of independent judgment and develop a sense of self-worth. In this phase the older adolescent may ask "Who am I when I'm not a daughter, a sister, or a cancer patient?" The literature does not describe how being diagnosed with a life threatening illness impacts these stages of development. Whether being faced with their own mortality hastens development or causes regression is not known.

Many writers try to distinguish between religion and spirituality and do so empirically but seldom articulate how different they are fundamentally and functionally. Charles Taylor (2007), a Canadian philosopher, tries (in his work *A Secular Age)* to address the shift from religion to spiritual. The secularization thesis holds that with the modern era and sophistication of technology and science, religion will gradually diminish, or has diminished, in its popularity and influence. Taylor's point is that the modern world has not seen the disappearance of religion but rather a branching out of religion, a new experience of it, or in some cases a growth in some areas. He supports the notion that there has been an awakening of a moral, political, and spiritual awareness. In the modern era we can have 'faith development' divested of religion. Taylor (1989) goes on in *The Source of the Self* to describe how modern/post-modern thinking is rooted in values, which are loosely tied to beliefs. He posits that these beliefs once seminal to identity are now mediated by values and address the distinction between spirituality and religious beliefs.

The social milieu of an individual, together with their value structure, gives a sense of meaning and importance to the concept of self.

Faith development theory is not standard practice in paediatrics, neither in ill nor well children and as a result little is appreciated about the inner private lives of children. Oser's theory focuses on stages in the development of religious judgment. He was especially interested in the developmental changes noted in children and adults with respect to the explanations they give for experiences they have that contradict religious belief (1991). Oser based his theory on interviews he conducted with individuals aged 7 to 75 and described five stages in the development of religious judgment. Three of these are no different to the typical stages of reasoning reached in childhood and adolescence, and a fourth develops in only a minority of individuals in adolescence. In Stage1 the view of God is concrete and literal and God is involved in everyday events of the world. If God is not obeyed consequences will be inevitable. The individual has little influence over God. This parallels Kohlberg's earliest stage of preconventional moral reasoning in which rules and laws too must be obeyed. In the second stage the older child and adolescent views God as less punitive and God can be influenced by the individual's good behaviour and observance. Stage 3 occurs in adolescence when religious judgment becomes more developed. God is seen as more distant and the individual is responsible for their own actions. The experience of stage 3 is directly influenced by the personal experience of the individual, both positive and negative. A recognition of human injustice is experienced in stage 3 along with increased questioning of the existence of God and increasing atheism. Stage 4 is experienced by a small number of adolescents, those that maintain a religious faith and turn to God wholly and rely on God's existence to make life meaningful. Oser does not suggest that all individuals will display religious judgments at the same stage or the same level of judgment.

Cognitive Functioning

As the adolescent develops so emerges cognitive functioning and interpersonal perspectives, described by Piaget as the early formal operational thinking phase. These young teens are able to appreciate abstract concepts, reflect on their own thinking and narratives and to begin synthesizing their own meaning. Some writers address aspects of hope in the context of developmental issues. In a paper on spirituality and child development McSherry and Smith (2004) make the point in their paper that the developmental needs of children must be considered in trying to meet their spiritual needs. In researching gender differences, Cantrell (2004) found that girls were more open to discussing these constructs than boys. Haase (2004, 2005) emphasized how age differences in adolescents influenced their cancer experience, again recognizing the dynamic developmental stages through which adolescents' progress.

Spiritual development has been linked to emotional and social development too. This is particularly seen in adolescence, when the development of mutual interpersonal relationships (Selman, 1980) emerges and where a focus on personal identity becomes all encompassing. It is during this stage of development that youth in crisis develop attachments to beliefs and values that are often seen as non-conforming. This stage of development lacks a third-

person perspective and youth are often unable to see and evaluate self or other relationships from a viewpoint other than their own perspective.

Work by Blustein (1991) on brain development in adolescents and the development of moral self is important in understanding developmental changes in this age group. There is no doubt that the normal adolescent is capable of recognizing selfhood: a teenager develops the ability to say ‘‘I’’ with meaning. However, it is not nearly so clear when the normal adolescent develops a moral self so that he or she can say with meaning, ‘‘I value this or that.’’ It is only once a teenager can express who “I am” in a moral sense, when the teen can reflect on what kind of person “I am” and articulate what is really important to “me” that they develop into an authentic human. This process is dynamic over time and individual. When an adolescent has not yet developed a moral self, his expression may not reflect values that are authentically his own true beliefs; values and expression of his own spirituality may not be possible.

Larson and Verma (Roehlkepartain, 2006) in their paper stress the importance that the experience of spirituality is influenced by macro societal influences as the adolescent enters and prepares for adulthood. These influences may include situations that they confront that in turn challenge their perception of their world. This further challenges their idealized personhood and idealized world. Seita and Tobin describe how spirituality may be hidden and inaccessible to adolescents in crisis and therefore may impact survival and hope. Helping the adolescent find this spirituality and give voice to it may contribute to their well-being and care of those suffering. Conversely, literature on abused adolescents finds that trying to make meaning of their lives is very difficult (Roehlkepartain, 2006). As a result these youth display poor adaptation and little hope.

Theorist	**Description of theory**
Erik Erikson (1902-1994)	Psychosocial development. Personal development influenced by social experiences. Described 8 ages of man: Infancy — Basic Trust Early childhood — Autonomy (Will) Play — Initiative (Purpose) School — Competence Adolescence — Identity (Fidelity) Young Adult — Intimacy (Love) Middle age — Generative (Care) Later adulthood — Integrity (Wisdom)
Sigmund Freud (1856-1939)	Child development in 5 stages of psychosexual stages. Oral (birth-18 months) Anal (18 months-3 years) Phallic (3-6 years) Latency (6 years-puberty) Genital (puberty-adulthood)
Jean Piaget (1896-1980)	Development of intelligence. Cognitive development. Sensorimotor (birth-2 years) Preoperational (2-7 years) Concrete operational (7-11 years) Formal Operational (adolescence-adulthood)
Lawrence	Adaptation of Piaget. Moral/ethical development.

Theorist	Description of theory
Kohlberg (1927-1987)	Pre-Conventional - Obedience and punishment orientation - Self-interest orientation Conventional - Interpersonal accord and conformity - Authority and social-order maintaining orientation Post-Conventional - Social contract orientation - Universal ethical principles
James Fowler (1940-)	Stage 0: Primal or Undifferentiated faith (birth-2yrs). Stage 1: Intuitive-Projective faith (3-7 yrs) Stage 2: Mythic-Literal faith Stage 3: Synthetic-Conventional faith (arising in adolescence; aged 12 to adulthood) Stage 4: Individuative-Reflective faith (usually mid-twenties to late thirties) Stage 5: Conjunctive faith (mid-life crisis) Stage 6: Universalizing faith, or enlightenment
Abraham Maslow (1908-1970)	Hierarchy of basic needs Physiological Safety Belonging and love Esteem Self-actualization Self-transcendence

Table 2: Summary of Developmental Theorists

Narrative Medicine

Rita Charon (2008) coined the term narrative medicine in 2001 as a means of telling stories of illness. This was a breakaway from the traditional evidence-based scientific approach to medicine to a more humanist approach to patients and their illness. Traditionally, medical narratives have been used in the clinical setting either as the doctor shares their patient's stories or the patient sharing theirs.

Physicians find that narratives enable them to talk simply and honestly, and that listening to the patient's story allowed a conversation around suffering, pain and the goals of care. Together the physician and patient could then have less of a scientific, rational discussion focused exclusively on the illness, and have a more meaningful conversation about the impact of illness on their beliefs and hopes.

Medical narrative is increasingly entering into the research arena, especially where the illness experience informs the research question as described by Prasanna (2011). This requires skill in understanding the multiple sources of meaning and interpretation. The narrative not only tells the story but also provides meaning, perspective and the context to an individual's illness. This provides a way to delve into the illness in a more profound way than with merely taking a medical history.

Conclusion

This literature review highlights the multi-dimensional nature of the question being posed: an enquiry into the role hope and spirituality plays in the lives of developing adolescent cancer patients. Numerous studies were reviewed and highlights that the lived cancer experience of adolescent patients is not well understood, and how they cope and make meaning of their diagnosis needs to be explored. When faced with fear and uncertainty what are the internal strengths that buffer them? When illness strikes at a critical time in the development of the adolescent, when relationships are compromised, social networks stripped away and the sense of 'being' challenged, how do these young patients make sense of their illness?

As clinicians engage with their patients they can acquire a better understanding of normal and pathological development of faith and identity (Fowler, 2004). Fowler speaks of the "radical secularization and the erosion of moral authority." It is in view of this secularization that adolescent spirituality versus faith is the concept that I want to explore further. In younger children spirituality has been defined as the ability to find personal value and empowerment mostly through valued relationship (Taylor and Amenta, 1995). Oldnall (1996) describes an individual spirit that is the "driving force giving meaning to life". This in turn defines the individual's belief structure and morals and their unique interpretation of suffering and illness.

Themes from descriptions of adolescents at risk, and the growing body of knowledge around resilience, both point to important aspects of coping in times of adversity. Of the many themes described in the literature, two specific themes, spirituality and hope, appear to be important. With my study I will further explore these concepts to add to the body of knowledge but also to guide supportive clinical initiatives and enhance communication. Evidence to support healthy adolescent development in youth faced with life threatening illness needs to be found. The value therefore of this research lies in the enquiry into the lived cancer experience of these patients and, with the knowledge gained, its utility in the clinical setting. The hope is that with greater conceptual clarity interventions tailored to the needs of this group can be better identified. We need more evidence to identify and support risk reduction strategies to foster healing. An exploration of hope and meaning of life among adolescent patients will be used to identify ways to foster hope and provide better support for these patients through improved care plans and communication strategies. The intention is to improve the care experience of these patients and ultimately to improve their quality.

'As long as clinical researchers feel the need to document and understand human phenomena, we are sure to seek new methodological alternatives.'

Sally Thorne

Chapter 3: Constructing the Study

Introduction

As shown in the literature review, much theory exists on hope, spirituality and the adolescent but little empirical work exists that actually captures the adolescent in the clinic and living through cancer treatment. The previous chapter reviewed the literature pertaining to adolescents, their developmental journey and resilience, and the literature surrounding hope, meaning of life and spirituality in health care. There is a need for further research, both qualitative and quantitative, exploring adolescents and their meaning of life in the face of a life threatening illness.

This chapter describes the philosophy underpinning the research approach and designs the aims of the study, the methods used and the analytic plan outlined. The participant characteristics are described, and I will discuss both the steps taken to minimize researcher bias and the important ethical considerations of this study. There may be some repetition in each of the separate headings in order to provide a complete description of each concept.

Research Question

This study aims to develop an in-depth description of hope and the meaning of life in adolescent cancer patients. This knowledge will help in holistically caring for these patients.

Aims and Objectives

To explore the adolescent cancer patients' perspectives on hope using interpretive phenomenological analysis

To explore the impact a cancer diagnosis has on adolescents' interpretation of the meaning of their life

Research Design

The research strategy chosen to address this question was a qualitative research approach. The basic theoretical underpinning of this study is one of induction. Although my research was guided by what is already known in the literature and attention paid to theoretical considerations, the basic strategy was one of inference and inducing knowledge (Bryman, 2004). In this study the subjective experience of each individual and their personal narrative of this

experience provided the raw data and insights, which I interpreted to identify themes. *Apriori* theory cannot address all the lived realities of these children, and theory emerged from their experience of their illness and their cancer journey. The epistemological basis of this study emerges from the health sciences and interpretivism, more specifically the interpretation of the subjective meaning of the participants.

There is a gap in the literature regarding how adolescents diagnosed with cancer experience their diagnosis. Especially lacking is literature focusing on the inner resources and assets these adolescents utilize in overcoming the negative experiences of their diagnosis, treatment and prognosis. Exploring these themes not only added to the existing body of knowledge but also explores existential issues and spirituality both of which are lacking in the literature. To understand the youths' points of view and really appreciate their 'lived experience', an interpretive descriptive approach was used. Commonalities existed but each adolescent brought his or her own unique expression of a shared experience or focus. The individual narrative helped ensure the adolescent's voice was heard even though they were describing a common experience. An example is receiving chemotherapy and being admitted to the ward.

Initially hermeneutic phenomenology was considered for this study as it specifically focuses on the meaning people make of their particular "lived experience". However in the medical context this methodology does not allow the researcher to draw on the existing body of clinical knowledge that already exists or provide theory to guide clinical practice. Traditional qualitative methodologies come out of the philosophy (phenomenology), sociology (grounded theory) and anthropology (ethnography) spheres and these methods do not always adequately address research involving human health (Thorne, 1997, 2008). Medical research in most cases has a body of knowledge already informed by quantitative methodologies and therefore brings a different ontology and epistemological viewpoint and requires a new theoretical lens.

Since the ultimate focus of this research is the integration of the findings into clinical practice, the ideal methodology is interpretive description as described by Sally Thorne (2008). Interpretive Description is an "inductive analytic approach designed to create ways of understanding clinical phenomena that yield application implications" (Thorne, Reimer Kirkham, MacDonald-Emes, 1997). Interpretive Description draws on elements both of grounded theory and ethnography and remains faithful to phenomenology. However, it also allows for thematic analysis of patterns, both common to and varying among and between, adolescents with a clinical diagnosis of cancer.

This methodology acknowledges the contextual and constructed realities of human experiences and has three basic premises. Firstly, that shared human realities can be studied collectively. Secondly, that in the nature of the engagement the researcher and participant influence each other and become "inseparable", and lastly, no *a priori* theory exists to encompass the human experience but rather that theory will be generated from the data (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004).

Interpretive Description is the exploration of complex experiential clinical phenomena, in this case, the experience of adolescents with cancer. Using this approach provides a framework for identifying themes and patterns within each participant's subjective perspective, then developing concepts and analysing the data in a reflective and interpretive way and exploring the important interplay with existing theory to inform a wider clinical understanding. Traditionally, Interpretive Description builds on small sample sizes and uses interviews, observations and other documentation, such as field notes or reflective diaries, to articulate a meaningful account of subjects' lived experience. An already available body of knowledge informs this.

In Interpretive Description, participants may be purposefully or theoretically chosen to reflect an awareness of the anticipated and varied experiences within the chosen phenomenon under study. In this study participants' own words will be captured and interpreted. I will pay attention to the timing and the context of each individual's expression of their journey.

Margarete Sandelowski (2010) has challenged qualitative description as a research design but as she later acknowledges this is a methodology that presents research methods as a living entity. This study deals with subject matter that requires an approach that explores the "living entity". Each adolescent constructs their own human experience using elements from their narratives that further explore the reality that they construct for themselves. No matter what methodology is used, adherence to rigor, integrity and trustworthy research remains paramount. The aim of this study is to generate knowledge related to a clinical context and practice and may generate new theory that specifically pertains to adolescents with cancer.

Philosophically this is a phenomenological study using an interpretive methodology. The narrative will be descriptive expressing the lived, subjective experience. A concept important to consider using this methodology is that coined by Gadamer, "fusion of horizons" (Lopez and Willis, 2004). This describes the fusion of what the researcher interprets with the meaning articulated by the participant and suggests that this interpretation is the researcher's own. This fusion of horizons needs to be honestly acknowledged in the interpretation, accepting that the researcher brings his or her own ideas, meaning and lived experience to the research. This is explored later in this chapter.

Interpretive Description is designed to guide practice by identifying themes in response to a clinical question. A critical and interpretive theoretical lens allows me to conduct and analyse the interviews. From a critical vantage point this assumes that the adolescents' cancer experiences are grounded in a personal, social and cultural reality. The interpretive lens also allows me to attempt to understand the participant's meaning of their disease and more specifically, how this disease influences their spirituality and resilience. The analytic focus is on the meaning these participants place on their life, coping and the processes or skill adopted to cope. Interpretive Description methodology is constructed out of a body of existing knowledge or literature. Even where little literature exists on a topic, clinical knowledge is equally important to consider. It is this

‘known’ element that serves as the foundation on which an analytic framework can be built.

This study therefore aims to develop an in-depth description of the cancer experience of adolescents and how this new identity influences their hope and meaning of life. This knowledge will guide initiatives to support these patients along their journey. The objective of this study is to explore the adolescent cancer patient’s perspective of their illness and what hope means to them. By using interpretive description I will explore the impact the cancer diagnosis has on their interpretation of their meaning of life and spirituality.

Methods

The method chosen for this study was to conduct in-depth interviews with the adolescents. These were unstructured and open-ended, as I wanted to hear their narrative and take a critical approach to the interview. Although this was a research endeavour, as Rita Charon described when referring to narratives in medicine, I wanted to have the “ability to acknowledge, absorb, interpret, and act on the stories” (2001, p1900). I wanted to hear “the words that contain the chaos of illness” (2006, p266). I wanted the youth to share their narrative with only direct prompts or trigger questions when the narrative went off focus. The available research provided a theoretical lens with which to help guide interviews. This theoretical lens was further informed by the interviews themselves and as the study progressed and themes emerged these themes were further explored with the participants.

Potential participants were invited to consider participation by an at arms-length member of the oncology team, either a social worker or the research nurse. Posters advertising the study were placed in the teen lounge and on notice boards in the inpatient and outpatient treatment areas (Appendix 2). The participants all had sufficient time to consider participation. The parents or guardian all read the consent form and had sufficient time to ask questions and discuss participation. If they agreed to their children participating they signed the consent and gave permission for the research team to approach their child. The adolescents had sufficient time to ask questions and consider participation and if they dissented they were not included despite parental agreement. For the adolescents, if they were in agreement they read and signed a consent form (Appendix 3) that explained the nature and focus of the study as well as how the study would be conducted. Participants understood that their narratives would be focused on the study topic. Verbal confirmation of participation was obtained before the interview began. Participants could choose when they wanted to be interviewed and this would occur in the clinic at the time of their clinic appointment or when on the ward at the time of an elective admission or an admission for a complication of their treatment.

There was an observational element to the methodology. Specific responses, overall demeanour, body language and display of emotions were captured in my field notes. These were described after the interview in my reflexive journal. My reflections and emotions were described separately and sometimes only after a few days. Throughout the study I had to recognize and acknowledge

that my relationship with the participants was inseparable from my clinician role. I will discuss this further in Chapter 4.

Setting

The research was conducted at British Columbia (BC) Children's Hospital in Vancouver, BC. This tertiary care centre is the only paediatric oncology centre in BC and parts of the Yukon and therefore draws patients from both rural and urban settings. All participants were undergoing intense therapies, had all been newly diagnosed and were within 6 months of starting therapy. Three had been treated with bone marrow transplantation. This allowed participants adequate time in their disease trajectory to experience chemotherapy, side effects and its impact on their lives. Patients deemed palliative were not eligible for this study. This group of patients was excluded from my study for a few reasons; I wanted to be sure the methodology was robust enough and ethically I did not want to subject a palliative patient to my research if the methodology needed revision. Although I think this group of patients is important to explore these constructs a separate study interviewing palliative care adolescents is envisaged.

Interviews

Eight interviews took place in the outpatient clinic setting and 5 on the in-patient ward. There was a possibility that children admitted to the ward might be sicker and that this could have coloured their interview but I interviewed them only once they were well enough and able to engage willingly in the conversation. Interviews took 30-90 minutes with an average of 58 minutes. All participants knew their narratives were confidential and that they could end the interview whenever they chose. The interviews were audio recorded and transcribed immediately by a transcriptionist, who had signed a confidentiality agreement. I checked the transcriptions immediately afterwards, listening to the tape and reading the transcripts. This helped me to immerse myself in the data and ensure reliable transcription. I wanted to be sure to capture the spoken words of the participants and the context of the interview. I assigned a set of unique, non-identifiable initials to the transcripts and, where names or obvious identifiers were disclosed in the transcript, these were erased. These audiotapes are saved in a locked drawer in my office, available if required for rechecking and re-analysis if needed. These will be discarded at the end of the study. Two tapes had jumbled areas in the interview, enough of the interview existed and I did not go back to re-interview those two particular participants (Steven and Nathan).

Analysis of the interviews

Thematic and discourse analysis methods were used to analyse the interview transcripts. This included my field notes, which were used to contextualize the interviews and collectively helped to explore the adolescents' experience with cancer and the aspects of hope, spirituality and coping. My personal reflection was recorded too. An example of a transcript, filed notes and coding are available in Appendix 5.

The themes that emerge may be common to, or varied among and between, individuals experiencing the phenomenon of a cancer diagnosis. The existing evidence that informed the interviews guided the methodology of thematic extraction. The interviews were unstructured and the participants shared their narrative with very little prompting. In retrospect a more structured nature to the interview may have made the data richer and increased generalizability and interpretation. This is discussed more fully in Chapter 5. Existing knowledge and emerging common concepts and themes became the foundation of a critical analytic framework which has been used to describe and analyse what is shared across the sample, and also to differentiate what may be particular to the individual. It is important to recognize that human health and illness is experienced as a complex interaction of the psychological, physical and biological realms. These participants have a shared experience but unique realities too.

From the transcripts I identified aggregate concepts or themes and the subthemes that united each theme. I did not confirm these themes and my interpretation of the interviews with the participants. This would likely have added richness to the analysis and helped affirm the credibility of the emerging themes. However, themes that emerged in the earlier interviews were explored in later interviews and this served as a means of triangulation or a way to cross check findings. Bryman suggests triangulation is “the use of more than one approach to the investigation of a research question in order to enhance confidence in the ensuing findings” (Bryman, 2004).

Researcher bias and my epistemological standpoint have to be acknowledged in the framework and fully explored in the analytic process. It was important for me to disclose my philosophical viewpoint and explore my own spirituality. I have not had cancer but cancer and illness clearly affects my everyday life. I needed to give voice to my sense of self. I considered having to explore my own reasons for doing this study, the nature of the topic and what meaning I brought to my own life. But in the end I had this discussion with our clinical ethicist. This was an important exercise to embark upon and helped me to identify – and perhaps to some extent separate - my own unique biases.

Having to critical analyse why I was doing this research and what bias I brought was essential to the integrity of this study and having to discuss it with a neutral person was the only way I was going to give voice to my motivations and opinions. To have chosen this topic for a doctoral dissertation already speaks a little to my bias. In the conversation we explored why I chose the topic. I see children every day who want to live, who have the capacity, despite a poor prognosis, to live while dying and I wanted to know why? I wanted to understand what it is that empowers these patients and where they find the strength. I believe in a holistic approach to care and that all children and their families are multifaceted and need care delivered in ways that work for them. I want to provide care within their cultural and societal constraints and how for me the healing is more important that the mere treating. I came to the research believing there was another dimension to patients and that they were spiritual beings; religious, secular, theist or atheist. This view would have prevented me from seeing a different viewpoint or reality. I was made aware of how my interview could have been perceived as coercive or unidirectional and to

remain open and curious was essential. That this exploration carried no ability to be disappointed and to remain critical was an important factor to remember. I was reminded to engage with the participants in as neutral a fashion as possible, remain interested, curious and receptive and to truly listen to their narratives. This was an essential component of my research.

To confirm my thematic analysis and probably reflecting my insecurity in the methodology, a co-investigator independently coded, synthesized and inductively analysed the complete body of data and the extracted themes and sub themes. Patton (Patton, 2002) encourages multiple independent coding and later comparisons looking for similarities and important insights that may emerge. However, too many opinions may hinder conclusions (Morse, 2006). An open coding method of data analysis was used, reviewing for repeated themes (Coffey and Atkinson, 1996; Cresswell, 2009). Themes were classified, categorized and coded as soon after the interview as possible. This allowed the analysis to be creative and allow for the interviews to become more focused over time.

I believe that immersion with the data was essential to conceptually develop the research and to build the theoretical framework. Relying on software analysis cannot substitute for manual analysis (Weitzman, 2000), so I manually coded, and although I had hoped to use QRS NVivo to input themes, I was happy with the correlation with the independent coding. This coding was comparable and these themes identified and confirmed the relationship with the data. The documentation in my field notes, my personal reflections and detailed analysis all contributed to the analysis. The co-investigator, who served as advisor, reviewed all documentation to help ensure face validity and reliability.

The actual coding of transcripts followed the following outline:

1. Complete review of transcript
2. Identify unifying themes
3. Identify phenomena and concepts (Strauss and Corbin, 1998) in each script
4. Colour coding of each concept and cross referencing with each transcript
5. Diagrammatic depiction of themes (Chapter 4)

How does the study design deal with minimizing biases?

I have to ask why I chose this research question. Have I designed it with inherent bias? Epistemological bias (Willig, 2001) suggests bias is at the very heart of the enquiry. This forces one to reflect on the assumptions and outcomes of the study. My clinical work clearly influences my epistemology, and I trust the rigor of this research will overcome this inherent bias.

As a researcher I bring to my research my own interpretation, and as a clinician my own “lived experience”. I have to reflect on my own values, beliefs and culture. The importance of relationship and the impact that this has on articulation and the richness of the contextual features are paramount. How the

researcher analyses the life-worlds (Lopez and Willis, 2004) of the participants has a direct bearing on the recommendations that may arise for practice.

The inherent qualitative nature of the study brings in my personal bias therefore I have employed reflective thought in this research. Keeping a reflective diary (Wall et al, 2004) is a means of bracketing. This allows me to separate my thoughts from those of the participants and encourages critical thinking. The sheer nature of qualitative research brings a subjectivity that introduces bias that Morse (2006) states are important and crucial in this type of inquiry. I have used a reflective journal to capture the research experience before, during and after the interviews take place. I have also undergone a session with a third party in which my assumptions, motivation and perceptions have been deeply explored. This, I believe allows bracketing in a real and profound way. My impressions, challenges and conceptual thoughts have been recorded. After each interview, I recorded my impressions and challenges and the value of the narrative. I have attempted to make sense of my own bias and emerging ideas as the study progressed.

I hoped to minimize bias by having different eyes review the data. Co-investigators were asked to synthesize the entire body of data and independently code and extract themes. Co-investigators included my practice–based supervisor and an arm's length colleague versed with qualitative methodologies.

Rigor and credibility

Interpretive Description is a well-established approach to qualitative research. All steps in the relationship of the data to the analysis will be transparent and disclosed. There will be systematic and rigorous evaluation of evolving findings within the context of the available body of empiric knowledge. Overall generalizability of findings and applicability will be disclosed in the analysis. DeWitt et al. (2006) describes 5 criteria for judging the rigor of an interpretive phenomenological study. These include a 'balanced integration' of the epistemology and the voices of the participants, 'openness' in describing the research process, 'concreteness' in the usefulness of the findings. Further describing 'resonance' as the felt response to reading the paper and lastly 'actualization', the response or resonance to the study findings.

In interpretive description it is essential to immerse oneself with the data while further synthesizing, theorizing and re-contextualizing rather than simply sorting or coding. Having another reviewer independently code the interviews, using open coding techniques, helped to ensure that all emergent themes were identified.

Population and sample

Discriminate sampling allows one to explore varied opinions and contribute to the complete theoretical framework (Strauss and Corbin, 1998) so the focus of my recruitment was to continue to enrol participants until no new themes emerged (Morse 1994) and themes began to be confirmed from diverse participants. Children with benign tumours were excluded in order to

concentrate on exploring the cancer experience. Children with cognitive delay were also excluded, not because their narratives are not important, but the impact of developmental maturity on the themes of hope and spirituality were important in this study. Only one participant had a brain tumour but he was fully functional and the interview was conducted before he received radiation, which has the potential to impact cognition.

Recruitment posters were placed in the teen lounge, and to minimize coercion, the research nurse and social worker explained the study to the child and provided study information and consent to potential participants. All children consented to participate and 13 participants were recruited. No personal identifiers were used; rather, a unique study identifier, created by random initials, was used to identify the transcripts. In the transcripts where names or obvious identifiers were used either a pseudonym or deletion of the name was employed. A random pseudonym was applied to each participant. Participant characteristics and the assigned pseudonyms are detailed in Table 3.

Pseudonym	Gender	Diagnosis	Age	Where Clinic/ward	Outcome
Rod	M	Leukemia	19	C	D
Basil	M	Solid Tumour	16	C	D
Sue	F	Leukemia	17	C	A
Jane	F	Leukemia	18	W	D
Linda	F	Solid Tumour	19	C	A
Queenie	F	Solid Tumour	17	W	A
Emma	F	Solid Tumour	17	W	D
Steven	M	Solid Tumour	15	W	D
Diane	F	Solid Tumour	18	W	D
Marc	M	Solid Tumour	16	C	A
Karen	F	Solid Tumour	15	C	A
Nathan	M	Solid Tumour	18	W	D
Michael	M	Leukemia	16	C	D

Table 3: Participant Demographics. A=Alive; D=Deceased

Description of participants

Thirteen adolescents participated in this study. All were 15-19 years of age and on active therapy: chemotherapy, bone marrow transplantation (BMT) and/or radiation therapy. One participant had experienced an early relapse and another had poor prognostic cytogenetics that required therapy with both chemotherapy and bone marrow transplantation. Both males and females were recruited and from a range of ethnicities. I have described the tumour type in a vague, more collective term in order to protect privacy. A detailed tumour type, age and gender would easily identify the participant, as this patient population is small. Although palliative patients were not recruited, eight of the participants have since passed away. These deaths occurred months after the interviews but the high death rate reflects the ‘adolescent with cancer’ demographic. Adolescents often have high-risk disease, requiring intense therapy, and carry a poor and guarded prognosis (Bleyer et al, 1997). Participants chose to be interviewed either in the clinic or on the in-patient ward. Timing of the interviews was fraught with difficulties. Timing had to coincide with the participants feeling

‘up to it’, not overly nauseated, not sedated, and at a private time when we would not have interruptions and I had flexibility in my schedule.

Ethical considerations

This research protocol was reviewed and approved by the Research Oversight Committee in the Division of Haematology/ Oncology/ BMT. This is a committee before whom all research in the Division is presented. The protocol is reviewed for its scientific merits, the impact on study participants and to ensure there is no other conflicting research. Following approval from this committee ethics approval can be obtained. Both the Bath Research Ethics Committee and the University of British Columbia’s Children and Women’s Research Ethics Board approved this study. (Appendix 4).

This research included a vulnerable population and special considerations were required. Full informed consent was required from parents or legal guardians as well as the child as per the BC Infant Act (RSBC 1996, Chapter 223, section 17). Adolescent assent would have sufficed from a regulatory perspective but I believed this was a research study for which the adolescents needed to express their own consent to participate. Even if the parents consented and the adolescent did not, from my ethical perspective they could not be included in my study. This fortunately did not occur but was an issue that needed consideration in advance. As I work in the oncology program and am known to the potential participants, confidentiality and protection of the participants were paramount, and this was reiterated with parents, legal guardians and participants.

Confidentiality was reiterated to all participants. However, they were informed that if they disclosed risk to themselves or others, suicidal ideation or abuse, by law this would have to be disclosed. Participants were free to withdraw at any time. This research potentially could cause distress, and this was disclosed up front to participants who were encouraged to stop the interview at any time if they felt uncomfortable. Although it was never required, a social worker and psychologist were available to debrief the child and offer immediate and or ongoing support if required. Two of the well-respected and referenced bioethical principles of ethical conduct were considered: respect for autonomy and non-maleficence (Beauchamp and Childress, 2009).

The power hierarchy had to be acknowledged and every effort was taken to ensure no coercion was perceived and that the protection of the participant was explicit. This power relationship begs exploration in the quality of the interviews and the information shared. Did the participants feel an obligation to give an account of their narratives in a specific way? Were they feeling judged? If they did not participate was their care going to be compromised? This power hierarchy will be explored further in Chapter 4.

Safeguards were put in place to protect confidentiality. The transcriptionist worked at the hospital but even so, she signed a statement of confidentiality. A unique identifier, using contrived initials, was assigned to all participants and this same identifier is used to identify the transcripts. Transcripts were coded with themes that emerged. These were coded soon after completion of the

interview and a coding system using numbering and colour coding was used. An example of a transcript and coding used is included (Appendix 4). I assigned an anonymous pseudonym to each participant and this pseudonym was applied to his or her words as verbalized in their narrative in the analysis section. The use of quotes makes the analysis more personal and brings humanity to their words. All research documentation and transcripts of the audiotapes are stored in a locked cabinet in my office and will be stored for five years as per University of British Columbia Research Ethic guidance.

Summary

In this chapter I describe the methods used to explore hope and spirituality in adolescents with cancer. This is a phenomenological study, underpinned by a philosophy of interpretivism. This study uses in-depth interviews and in this chapter I discuss the importance of personal reflexivity in the methodology. The participant demographics are described and the recruitment and consent process explained. The participants in this study are vulnerable and the ethical consideration and lengths to protect them are described. In the next chapter the findings and interpretation of the data will be discussed.

"Gathering up the reasons to hope.
That is the real fight against cancer"

Participant Steve

Chapter 4: Narratives

Introduction

In this chapter I will present both the findings as identified in the transcripts and my analysis of the findings. I will include an interpretation of the data in this chapter too. The interpretation is so interrelated to the findings that to separate the analysis and discussion into two distinct chapters would not serve this study well. The analysis of this study follows traditional qualitative guidelines. The following criteria are typically applied to analysis using interpretive description (Thorne, 2008 p 223); these being epistemological integrity, representative credibility, analytic logic and interpretive authority.

Epistemological integrity requires that there is clear reasoning and coherent flow in the research process, from the question being asked to the logical interpretation of the data remaining faithful to the epistemological standpoint. In this study exploring hope in adolescents, I want to evaluate their experience of their disease, their inherent knowledge of hope and what it means for them, rather than any preconceived notion of what hope is.

Representative credibility speaks to the ability to confirm that the constructed perceptions are indeed generalizable to the group under study. Sandolowski (1995) observes that triangulation of the data adds to the value of the knowledge claims, and that there is more than one way of interpreting data. In this study the phenomenon was a shared one amongst the participants in that they all had cancer but they represent a heterogeneous group by virtue of their cancer diagnoses and the diversity of their cultural groups. As knowledge was gained through the interview process, in the latter interviews I explored certain themes purposefully in an attempt to gain a deeper understanding and allow a degree of triangulation.

Analytic logic requires that the reasoning process is clearly explained and evidence produced to support claims. Leininger (1994) suggests that a clear reasoning pathway be described so readers can follow the logic of the claims. In this study verbatim quotes will support research findings and make the reasoning explicit. In order to enhance confidentiality a pseudonym has been assigned to each participant and the words of the participant acknowledged with this pseudonym.

Finally, qualitative studies need to demonstrate interpretive authority. It is accepted that the acquisition of knowledge in qualitative research requires a certain degree of subjective interpretation. This bias needs to be clearly disclosed and that the interpretation is transparent and portrayed in such a way

that the interpretation does not reflect the researchers' own bias. Equally, interpretive authority requires that the claims made are clearly individualized based on the words spoken by the participant and not simple generalizations. In this study my interpretation of certain themes and statements were explored and validated by having other reviewers analyse the interviews independently.

In her book Sally Thorne (2008) describes how health science research needs to be 'morally defensible'. It should be clear why the knowledge we are extracting from research participants is important and worthwhile and not a waste of their time. I cannot agree with Dr. Thorne more, and in this study I have tried to really focus on why this question is important and to what extent the knowledge gained may eventually influence practice. It was for this reason that palliative patients were not eligible for this study. Not because their lived experience is any less important or because understanding what hope means to them is not essential, but I wanted to evaluate the feasibility of this methodology and obtain the results from this study before engaging palliative patients.

Sadly, adolescents and young adults diagnosed with cancer tend to have poor prognostic tumours and as reported by the National Cancer Institute Cancer the SEER data confirms that adolescents have inferior overall survival compared to younger children (Bleyer, 1997). This poor outcome has been reflected in this study. Although no participants were deemed palliative when enrolled, since commencing this study in 2012, 8 of the 13 participants have died and 1 is now on active palliation.

Before I describe the narratives and findings from this study, I want to contextualize this study and discuss some of the philosophical underpinnings of this study.

British Columbia Children's Hospital is the only tertiary care hospital for the children of the Province of British Columbia in Canada. All children from birth to 17 years of age are accepted at this hospital and special permission is required to accept a patient older than 17 years of age. An overage patient would be admitted to the Children's hospital if they have a specific paediatric diagnosis and will be best served in a paediatric hospital. All children receive their work up, diagnosis and initiation of care at this hospital under the direction of a paediatric oncologist. The paediatric oncology unit is an active academic unit and an attempt to enrol and to consent or assent children on clinical therapeutic trials or biology studies are keenly sought.

Treatment for paediatric cancers tends to be intense, requiring admission for the delivery of the chemotherapy and the relocation to Vancouver of many families as their child receives treatment. If therapy is not too intense - in the case of maintenance therapy for acute lymphoblastic leukaemia for instance, then the child's therapy can be delivered in their community hospital under the direction of paediatricians.

Adolescents in this study were recruited from the oncology unit both from the in-patient ward and from the outpatient clinic. Advertisements were placed in the teen lounge and on notice boards on the ward. Either the research nurse or

the social workers recruited potential participants. We have a care delivery model where the oncologist on call for the ward is responsible for all new patients and then assumes the ongoing care and responsibility for these patients. In essence these patients become the oncologist's "private" patients and they follow these patients from diagnosis through the trajectory of their illness and into long-term follow up.

All adolescents diagnosed with cancer in the preceding 6 months were eligible. They needed to be English speaking, not palliative and cognitively able to participate. Those who met these eligibility criteria were recruited and all were interviewed on site. Those studied included some who were my own patients, and their inclusion leads me to discuss a philosophical concern I have with this study.

Power and the Participant

Michel Foucault (2010, p131), observes that power relationships are deeply rooted in our social nexus. He goes on further to say, "the medical profession is not criticized primarily because it is a profit-making concern but because it exercises an uncontrolled power over people's bodies, their health, and their life and death". In this study, especially given the vulnerable nature of the participants and the sensitive nature of the issues being explored, I believe it is important to recognize and disclose this power relationship and consider the implications in the context of this study. Apart from my role as the researcher, I also bring to the research my role as an oncologist, and in some cases my additional roles as treating physician, a senior member of the oncology team and the principal investigator of their clinical therapeutic trial. Although steps were put in place to have arms-length recruitment and both a written consent followed by a confirmatory verbal consent before the interview began, I was very conscious of the perceived power dynamic.

One could argue that by consenting to participate the adolescent has fully considered the study and acknowledged any risk equally one might claim that if they were feeling too vulnerable they could simply decline participation. However, consenting to participate is not sufficient evidence to dismiss a power differential and, in fact, Eric Kodish (2014) has shown how poorly participants understand the implications of consenting to participate in research. I believe articulating that this tension existed is important to the integrity of this study, and it was necessary to take measures to mitigate the power relationship. It is important for me to remember and stress that two elements exist, interrelated to each other; that the participant, over whom the power is exercised, remains an individual, a unique person, sharing privileged and sensitive information; and for the researcher, who holds the power, to recognize and appreciate the vulnerability of the participant and to value the information shared. Adolescents in this study provide a fascinating and authentic insight of themselves. While one may argue that a power differential existed and that the disclosures and narratives were not authentic the sheer depth of emotion shared makes me believe they were in fact authentic.

Recruitment to the study was slow, partly as a result of the rigid eligibility criteria, other competing studies and a desire not to overburden study

participants with numerous research studies and clinical trials, but also our total number of adolescent patients was lower than expected during the period of my study. Interviews took place either in the clinic or in the participant's hospital room. The shortest interview was 30 minutes and the longest 90 minutes, with an average of 58 minutes. Despite engaging in sensitive and potentially distressing conversation only two participants cried during the interviews and when asked if they wanted to stop the interview, neither chose to do so.

Five major themes emerged from the interviews, (Figure 1). These, related subthemes are depicted within each section in this chapter. I will describe these themes and validate them where applicable with quotes verbatim from the interviews. Anonymous identifiers (pseudonyms) have been provided with the quotes. I elected to use pseudonyms rather than initials as I believe it brings a more personal, human quality to the voice of the participants. In this chapter I have included comments from my field notes and some personal reflection but Chapter 5 will contain more detailed reflection.

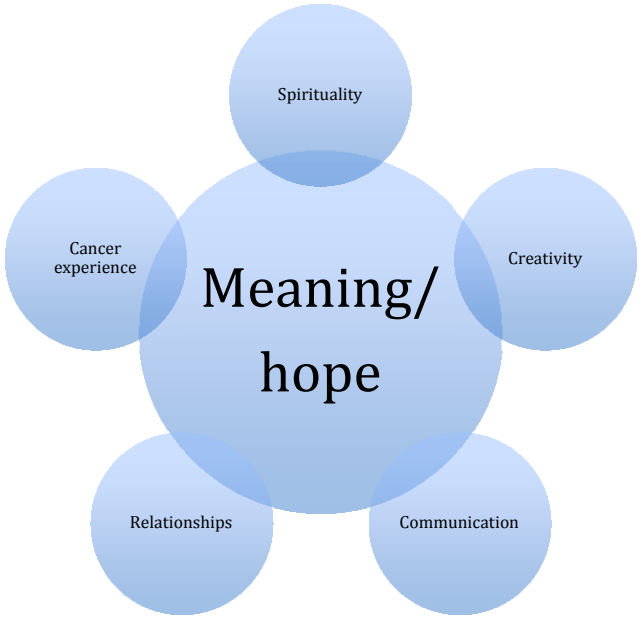


Figure 1: Emerging Themes

All narrative interviews were transcribed. Initial reading of all the texts provided a naïve understanding of the text. I then went on to code the text into sub-themes from which the 5 main themes emerged. I then reflected on how these themes compared with my naïve understanding from the initial reading and my participation in the interview. Finally I read each interview as a whole again and considered whether the themes I had identified aligned in relation to the available literature concerned with my topic under study. I wanted to confirm that my themes regarding the meaning of lived experience in these cancer patients aligned with the literature on other population groups with a chronic disorder, such as patients with HIV, chronic kidney disease or cancer.

As I reread each interview I was reminded of Neitzsche's remark that, "There are no facts, only interpretation", and I hope my immersion with the interviews presents a comprehensive understanding of the world of the interviewees as configured in the interview and then refigured by myself and then by you the reader.

Narratives give insight into the "private self" (Charon, 2001) and when exploring the lived cancer experience of these adolescent participants and how this diagnosis influences their meaning of life and their spirituality, five major themes emerged. In no particular order of importance these domains were; the cancer experience itself, relational, communication, spiritual and creativity. I will discuss each theme in separate sections and within each of these sections further elaborate on the sub-themes that emerged.

Section 1: The Cancer experience

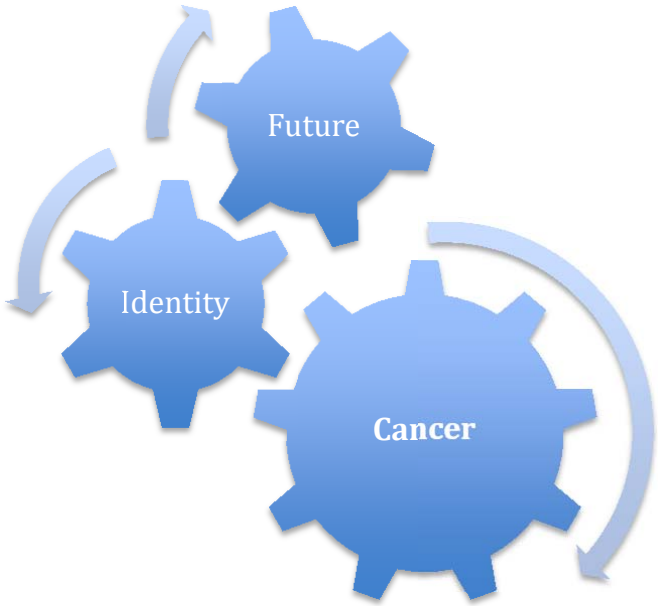


Figure 2: Cancer Theme with Sub Themes

Identity

All children go through a process of development, becoming unique individuals, and in due course become autonomous persons. Work by Blustein (1991) on brain development in adolescents and the development of moral self is an important aspect in understanding the developmental changes in this age group. There is no doubt that the normal adolescent is capable of recognizing selfhood: a teenager develops the ability to say ''I'' with meaning. As the adolescent develops so emerges cognitive functioning and interpersonal perspectives, described by Piaget (1965) as the early formal operational thinking phase. These young teens are able to appreciate abstract concepts and reflect on their own thinking and narratives and to begin synthesizing their own meaning. A more contemporary theorist on development, Michael

Berzonsky (1992), explores identity style in adolescents and defines identity as the “different ways individuals construct and revise or maintain a sense of identity”, especially when faced with stressors that may impact the adolescent’s pre-established sense of identity.

There is a dearth of literature that describes how the identity style is altered by the diagnosis of a life threatening illness but if one views identity as a form of problem-solving or a coping mechanism then these adolescents would likely construct their identity within the context of their illness.

The adolescents interviewed all had cancer but only a few identified who they were with a cancer diagnosis – they described themselves initially with aspects of their lives that they related to and what brought them meaning. Further, it was often these activities that the participant missed most and looked forward to restarting in the future. These adolescents described themselves first and foremost in relation to their social and contextual realms related to their age, activities, school or hobbies foremost, before their diagnosis.

“I’m 17 and umm…I do lots of art work and paint a lot and umm, I like playing with my dog.” (Jane)

“I’m 18, grew up in North Vancouver, lived there my whole life and I have AML leukemia.” (Rod)

“I am more than my diagnosis – more than this… can…my medical condition.” (Steve)

Cancer seemed not to define them but was inextricably linked to who they were. The cancer diagnosis appeared to be a more immediate “identity” but their reference to their future was a cancer free one.

“This is what I’m meant to be doing right now, gives me my identity. I think people at school would be like oh that’s the kid with cancer… whatever. I don’t see myself as myself.” (Basil)

“Think of the things you like to do, like to do in the future. Don't let the sickness bother you when you're nauseous for example, don't think "Oh, I'm nauseous because I'm sick, just think I'm nauseous because I don't feel well today and I can get better tomorrow.” (Marc)

“When you are diagnosed with something like this you kinda just have to look at everything on the bright side of things, forget the negatives, ‘cause then it will be that much harder to get through.” (Emma)

They described an acceptance of the diagnosis but linked it to a determination to have a positive outcome. Some participants spoke to a gratefulness and specialness in being diagnosed. They identified themselves in some way as having been ‘chosen’.

Here, Emma and others speak to being special.

"Have I figured out why I have cancer? I wouldn't be the person I am today if this didn't happen… and I don't wish this or any part on anyone, 'cause it's hell to go through… completely… especially when you're trying to finish high school… and … I mean… I graduate next year and I'm trying to get my life back in order and I just, I, I'm grateful that it… like I'm grateful that it happened." (Emma)

"Just it's a fight and like a boxer in the ring, like a hockey player on ice, it's a fight to win and I'm fighting to win." (Linda)

"I never really thought why me, I thought why not me because I probably, I have the energy to do this." (Nathan)

"Well there are reasons for everything. Bad stuff happens to good people, umm, because they are special for a certain reason." (Emma)

Future

Adolescence is a unique developmental stage requiring considerable adjustment and these young people share common characteristics during these years of transition. These include a feeling of anticipation for the future but with regret for their lost childhood. Participants believe that they have the capability to make things better, to be cured and make things happen for themselves in the future. They uniformly demonstrate an engaging in, and an embracing of, life. They seem to embody hope and expressed a sense of being inherently hopeful. Here, two teens share this sentiment.

"I'm not sure, I sort of, even at first, I thought Oh my God like I should be dead right now or like you know… why, like, why would I still be here… like why can't you just kill me now, or … but I never even actually really thought that because it's like well, why did this happen and it was like what was the reason for this happening. And I think it's also the younger age… it's like we haven't lived life yet, we haven't experienced the world and it's like we want to get out and explore. You know like I think older people are like, well I've lived a good life, that's it. Like I'm done." (Linda)

"Better days will come." (Queenie)

And later in the interview

"I started to realize this is a really good life experience. Whatever comes after I can definitely face, 'cause this is a big bump and I'm pretty sure after, after this life experience there won't be as big a bump, right? So... I, I just think positive." (Queenie)

Ronna Jevne (2007) speaks about hope being possible in the face of uncertainty and although hope was not always in the forefront of these young people's consciousness they were able to give voice to it.

“It’s been a really tough journey and been tough and it hurts but it should strengthen me for the future. Like I don’t know… like not sweat the small stuff and appreciate life.” (Basil)

After the diagnosis some adolescents indicated a thought process where they clearly considered the meaning of their lives followed by a thought process directed towards the future in a way that seemed meaningful to them individually. This is expressed by Basil in the quote above and again expressed by Linda and Steve below:

“I have this weird belief, where it’s like you know, once you’re kinda finished with your purpose on Earth then you will die afterwards. So it’s like you’re here to fulfil your duty and then pass away. And so I’m still here, I have to do my purpose.” (Linda)

“I find feeling sorry for myself is easier to do, it’s pushing the limitations of cancer aside, gathering up the reasons to hope, and reminding myself of the things I’m looking forward to that is far more rewarding but a scarier struggle. That’s the real fight against cancer. Symptoms can be treated but there is no way they can tell you how to fight back against the fear and the negativity cancer drags into a patient’s mind…and in those dark moments I find my mind is the scariest place to be but is somewhere I need to go to be able to carry on. I can’t possibly begin to fight with the same ferocity that I have before if I don’t acknowledge my fear and weigh them up against the hope that allows me to keep buggering on.” (Steve)

“I know I don’t look the same and I may feel insecure about them right now, but I know that later on when I throw a little more weight on, I have my hair back, I gonna feel amazing and I can’t wait.” (Emma)

“In my mind I’m healing myself and that kind of gives me that hope.” (Emma)

“I’m put at a bit of a standstill where I kind of have to put my life on hold to do treatment. I think it gives me more motivation to say ‘no wait, you wait for me to be done with my life first and then!’” (Linda)

In summary, these adolescents continue to develop their own identity, in the context of their social and contextual milieu, developing a sense of self clearly referenced in the future. Their present diagnosis and trajectory of treatment colours the uniqueness of who they see themselves as but that a cancer free future is what they direct their hope towards.

Section 2: Relational

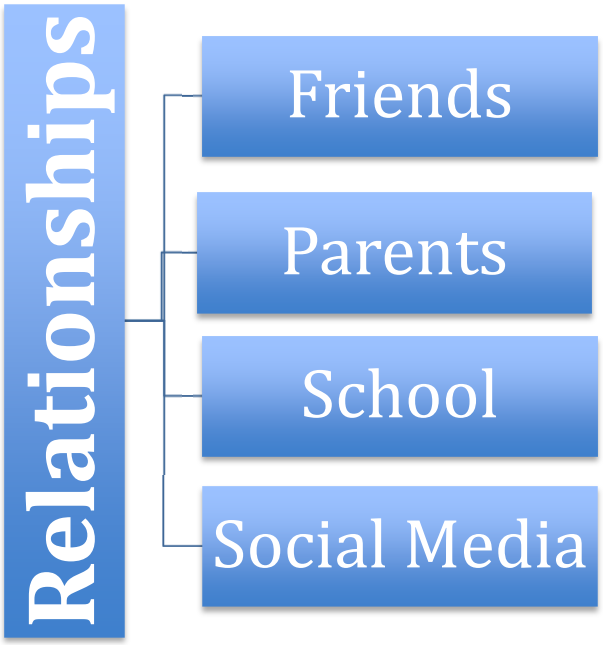


Figure 3: Relational Theme with Sub Themes

One of the themes that emerged consistently as giving meaning was that of relationships. This has also been borne out in the resilience literature, summarized in a paper by Bonnie Benard (1991), where she describes numerous studies (both longitudinal and ethnographic explorations) that have all provided a clear indication that resilience is a process of “connectedness, of linking to people, to interests and ultimately to life itself”.

In this study the researched adolescents used conversation to define themselves first and then their cancer experience. They used the opportunity to share their narrative to describe how their disease influences their life but how they have hope for the future and how the actions and perspective of others influences their appreciation and quality of their lives. This included family, friends and health care workers.

Friends

Firstly, I would like to address the role of friends as described by this cohort. As the adolescent transitions from childhood to adulthood they have two intertwined developmental tasks to deal with: the development of their identity as discussed above and separation from their family. Some teenagers struggle with the complex psychological development that accompanies these maturational tasks as they ask themselves: "Who am I?" "Am I ready to leave my parents and be my own person?"

Addressing the first question, "Who am I?" is a lifelong process of self-

discovery that is intensified in adolescence and discussed previously in the section on identity. Teenagers start transitioning their identities from their families to their peers, which is an essential and healthy part of normal development. Adolescents begin to define themselves – how they have fun, what music they like to listen to, whom their friends are, and how they dress. They begin to define themselves, what they're "about", where they fit in – often aligning more with their friends' lifestyles and choices rather than that of their parents. Often these attempts to fit into a group leads to belonging to a clique, having rigid ideas about what people "should and should not be like." This rigidity typically loosens with age, but teenagers rely on it initially because they often feel very lost and uncertain about who they are and where they fit in.

Teenagers usually feel anxious and self-conscious about who they are and what kind of adult they will become, still caring a great deal about their parents' opinions of them. All participants described the importance of friends, the need to remain connected with friends and, even as they were undergoing therapy, the need to be included.

“Seeing friends and just getting out and doing stuff. Just have to carry on. They (friends) take me out of myself and do activities.” (Basil)

When asking what sustains Emma she responds:

“My friends, I can’t have people dampening my spirits, and social media, I don’t see them (friends) often because they’re all busy with their lives and I don’t go to school but ummm, yep, they contact me every now and then or I’ll contact them. When I was a normal teenager going to school everyday... I would talk to my group of friends and mind my own business. I talk to everyone now…I smile… I hug. It’s true when someone says just smile at someone. It will make their day. It really does because you don’t know what they go through every day.” (Emma)

“You find out who your real friends are through this for sure. The ones who have stuck around are definitely the ones I will probably keep for life because they have been like really supportive. Sometimes like when I’m having a bad day and I don’t want to talk to my mom, so you turn to a friend.” (Linda)

Some kids spoke about a sense of isolation when it comes to friendships.

Queenie expressed how not going to school isolated her but she had met a kid at the hospital.

“We’re cancer buddies.” (Queenie)

Marc, an only child, described the role of friends as follows:

“Well my parent’s friends, they sometimes, they just come over and they don’t really mention that I’m sick or anything so that helps a lot and makes me feel like nothing has changed.” (Marc)

When I further enquired about friends his age, he said

“Um, yeah, well my parents’ friends’ children are also my friends. They go to the same school as me and they’ve been close friends.” (Marc)

In summary, during adolescence friendships are viewed as important. In my cohort the quality of these relationships becomes more vulnerable, trusting, and intimate. In the process of normal development friends become more important than parents and intimate relationships develop. The number of casual acquaintances rises as the youth expands his or her social network and begin to use more sophisticated communication technologies. This is arrested during the isolation of treatment, but the importance of friendship is still evident.

Parents

The other fundamental developmental task in adolescence is the process of separating from the family, both psychologically and often physically as well. "Separation" in the psychological sense is intertwined with the process of identity development; it is answering the questions described above: "Who am I, and how am I different or alike from my parents?" (Blos,1979). It also involves adolescents' struggle with wanting to be independent and caring for themselves, and their fear that they will be unable to do so (Josselson 1980). Although teenagers usually work hard to hide their insecurities, internally they question if they will be ok on their own. They also subconsciously wonder if their parents will cope when they leave home.

Adolescents' struggle with separating is reflected in their insistence on being independent and the desire to be treated and respected like an adult while often acting in ways that do not deserve this respect, and actions that do not reflect adult capacities or responsibility.

In some instances separation is also a physical act, in the case of older teens leaving home to attend university or leaving home just to be independent. In many ways, separating psychologically is sometimes facilitated by the act of leaving home to attend university or other postsecondary educational settings.

In the case of adolescents, the diagnosis of cancer disrupts this developmental separation, where a natural separation from parents would be expected. The new reliance on parents does not reflect a lack of cognitive or emotional maturity on the part of the teen, but rather the magnitude of the disease, the decision-making around therapy and often the physical need of the parents. This expressed need and dependence on parents was strongly expressed. Interestingly, the role of mothers was a very clear sub theme. In one case the adolescent’s mother was predeceased and the need for the maternal presence was so strong that she described her guardian angel always being present and she physically expressed this in her artwork depicting this angel.

“My mother died and she is my guardian angel.” (Jane).

“Definitely my mom, would say my mom for sure. She was there as much as she could even... even sometimes too much for me but you know it’s your mom. I’d much rather complain about her being there way too much than where the hell are you.” (Rod)

“My family. Both my mom and my dad.” (Basil)

A voiced appreciation of their parents was also expressed.

"My mum was prepared, as always. It seems like she always has the right pill in her purse or her pocket. I know I can be hard on my folks sometimes because taking all these meds can become repetitive and annoying, but I feel I take both her and my dad for granted a bit too much. I think I need to remember that they have to deal with me whatever mood I'm in." (Steve)

" I'd say my mom because she just has that motherly…it's spe-… like our time together is special and she's lies comforting me and …telling me never give up and don't quit." (Emma)

"My mother was there 90% of the time, my dad had to work." (Nathan)

Rod articulated this appreciation in not wanting to upset his mother.

"So I never wanted to say or have them say – 'oh you're not doing so well'. Especially my mom, I didn't want to see her upset so I put on a smile, I wasn't always happy, but I just wouldn't be all mopey and stuff." (Rod)

In another case both the participant and her mother were receiving therapy for cancer and she felt very strongly that *"I am my mother's mother." (Diane)*

Although parental relationships were described as being important, in one case the values were misaligned and her mother in this case, viewed as being too controlling. Here she intimates wanting her independence and the need to have natural separation.

"My mother is too controlling and because I have cancer she thinks I'm a baby." (Sue)

The disability literature describes the phenomenon of controlling and over vigilant parents more commonly than the adolescents in my study expressed this view. Granted my cohort is small, but in my group the increased presence of parents appeared to be accepted. All my participants spoke positively of the presence of their parents. Only two, Rod and Nathan, mentioned that they would have welcomed more separation from their parents.

"I just gotta keep smiling and do it, my mom just wanna helps too but I have to do this on my own." (Nathan)

Once discharged*…" I don't see any of the people that I used to see on a day to day basis, there's no doctors, nurses, all that you see is your mom and you know it's… you kinda get sick of seeing the same people. And you know it's just always the same ahaaaaaa, 'what you eating'-not much – or 'what can I make you to eat' or 'what can I make for you, what will you eat'…ahhhh." (Rod)*

I would be remiss to neglect to mention siblings. While siblings were certainly acknowledged in the narratives, sibling relationships did not emerge as a sub theme of importance. Similarly, the relationship with nurses was voiced more

than with doctors, but again without significant value placed on these relationships in the narratives.

"Some people find it weird but I have some good memories. In fact most of my stories are fun stories. You know something we did with nurses or something- you know - I have met so many really smart people and so many dedicated people. My peers went from teenagers to people mid 20's to somewhere mid 50's, maybe older. Ummm so the conversations are more mature but at the same time since I was so much younger than them (nurses) they allowed me to say whatever" (Rod)

"I would have the most energy at night time. It would be 3 in the morning, and it's like there would be nobody awake even some of the nurses are sleeping some talk to me on their breaks and stuff." (Rod)

Rod describes the relationship he has with nursing, a friendship and refers to them as peers but other participants did not discuss this relationship. This finding - especially the relationship with nurses, surprised me as nurses spend an enormous amount of time with the patients and often invest a lot of time building relationships and trust. As I described later in section 5 it was very important for the youth to feel medically informed and the importance of truth-telling is highlighted. The relationship with the medical team may be viewed as more professional as opposed to friendship. The relationship with the health care team is seen as important in facilitating rational thought and for allowing truthful conversation around shared medical information and for engendering trust in the health care team and not seen as a relationship of confidant or friend.

School

For most adolescents, school is a prominent part of their life. It is here that they develop key cognitive skills, develop friendships and foster important relationships with adults other than their parents. For some youth, school represents stability and routine. When a positive family environment exists for adolescents, the same factors that are identified in this relationship are identified as positively supporting the adolescents in the school setting, allowing a positive school experience (Resnick et al, 1997; Klein, 1997).

The importance of school was not a theme that I anticipated to be so prominent but one that was universally discussed. I had anticipated that there would have been an acceptance of not being able to attend school and almost a reprieve from school. However, school provided opportunity for connectedness and a sense of being normal. Attending school spoke more to the social engagement as opposed to the academic one. The loss of academic time and not being able to attend university was not a theme expressed. Being able to attend school conveyed a sense of the future and of being "normal" again. This quote from a grade 10 student really sums it up.

"Yeah because when you're in school, travel and stuff like that - just be normal again. When you're in school you really want to be able to do well, be normal. It gives me a sense of umm like normalcy, socially and physically and you can

see a future. It's more the social aspect of school." (Basil)

"I can't wait to be back at school. I can't wait to be back… aaahhh I'm just going to say this all the time." (Marc)

These sentiments were echoed by others:

"I just… I've always loved school. Like I'm just… always happy to learn about something and I'm happy to be with people, That's one of the things I found hard was missing out on everything… and well right now, since I'm a senior, probably the social part of it because all the senior fun stuff and that I'm missing out on, but I mean it's not my twelfth year, it's only my eleventh and all the fun stuff will happen next year, but I mean I'm getting older and I like to have fun too (laughs)." (Emma)

"When all the weight came back… that was another big step. Going back to school was great but when I first came back you know, I would just catch waves of nausea and have to be still and think… but whatever I'm at school!" (Rod)

Going back to school was the metaphor for being 'normal' again, being cancer free and being cured. This was a strong sentiment expressed by these youth when thinking of returning to school.

"Normal, it's normal. I think that was the biggest thing." (Rod)

"And I was thinking, if I gave up then if I was gone out of earth then I wouldn't see myself graduate. I wouldn't see everything that's so meaningful in life." (Queenie)

A few participants spoke of "not fitting in", of feeling they had grown up during their cancer experience. This may just reflect the normal developmental trajectory of adolescents and may not be related to the added cancer experience. But it might also reflect a disconnectedness resulting directly from the separation occasioned by hospitalization. As one participant put it:

"When I left, when I left high school, I was half way through grade 10, alcohol wasn't that big yet but when I got back people would go to parties, lots of people were drinking and there was more and more. And so I had kinda grown up, this was not for me and it is tough to settle back into my circle 'cause I didn't fit back in the same environment." (Rod)

There are marked individual differences in cognitive development among youth, and youth reach stages of mature decision making at different times. The attainment of cognitive competence includes the ability to reason, to problem solve, to reflect and to plan for the future. Emotional development occurs uniquely and at different chronological times for different groups of adolescents.

In summary, these adolescents are able to articulate that they feel able to achieve balance and satisfaction in their relationships with others despite the altered social networks within which they have to now function. They continue to have a relationship with friends that they express as not being ideal but that seems to fulfil an important need for the participants. In these interviews no

romantic relationships were discussed. Circumstances, the cancer diagnosis, created an interdependence with parents that were out of the norm for developing youth but the youth expressed a real respect and appreciation for this engagement. The interviewees gave voice to the hope of returning to school and a sense of returning living as normally as possible and of the experience of having a confirmative relationship as an important dimension of their lived experience of hope.

Social media

Recently media such as the Internet, social media and television have become an important part of adolescent lives. These media provide both a means of interacting and a vehicle for academic work. These new communication technologies include email, chat rooms, mobile phones with "texting", online social networks such as Facebook® and Twitter™, video communication such as Skype®, and online gaming (Girl Scout Research Institute, 2002; Rideout, 2001) and enable youth to create and to maintain social bonds in completely new ways. These technologies have been able to expand the size and complexity of social networks as well as their geographic reach. Youth are now able to relate to each other in different ways. They are able to influence the length of time and the time of day they spend connected with each another. The whole notion of "friend" has been redefined and the ability to have a virtual relationship is now a reality. The Pew Research Centre in a 2015 report commented that a typical teen would have 145 Facebook friends (Lenhart, 2015). The U.S. Department of Health and Human Services published an on-line newsletter on Teens' social media use and what it means for health. This used survey data from Pew Research Centre and corroborated that teens are sharing their health and personal information on line. www.hhs.gov.

Although this mode of communication is now mainstream it emerged as a theme described by the youth as a positive way of remaining connected. While one participant mentioned using the Internet only as a way to keep up with homework as this was an important part of whom she was.

"I've been trying to keep up as much as I can with school work because I want to graduate on time and I think it's really important and I try to keep up with it and it gives me stuff to do too." (Jane)

In most cases media use was primarily to stay connected with friends.

"*I usually message on Facebook, then I stay in touch." (Basil)*

"I've had like two or three friends that I just tell absolutely everything to. Generally through text message. That's what… what makes me thankful for social media." (Linda)

"I think I'm more attached to my phone than ever, cause it's my contact to like, all my friends and my family." (Emma)

"So I didn't see them as much in that in between period. I more talked to them on the phone or text them or on Facebook but there wasn't much real human interaction." (Nathan)

A sub-theme I expected to emerge was the role of support groups in fostering hope and encouragement. I know a number of the participants attended the teen support group but only one youth mentioned support groups in the interview.

"I haven't gone to any of the support groups or anything." (Basil)

Although I did not explore this further in the interviews when I discussed this after the study with teens the teen group was seen as an extension of the hospital and just one of the programs routinely offered. This was viewed as a positive bonding experience where they could all "hang out" together but friendships outside of the teen group was seen as more vital and sought after. One participant saw her circles of friends as different:

"We're cancer buddies." (Queenie)

Reflection

A number of the interviews were with patients for whom I was primary physician. These were easier interviews and the difference in the level of comfort was quite palpable. The first interview was with a patient I knew but not my own patient. At the time I commented in my field notes that I was frustrated that I was not "getting deeper" – not that I could quantify this or even knew what I had expected to come out of these interviews. I had to trust the process and put aside my expectation that I would hear profound words of wisdom. I had to trust in the narratives and trust that they were authentic. More than this truth I could not ask for. This first interview helped allay my fears that only children who wanted to talk about 'religion' would participate. He really wanted to talk – to *"give back"* as he said but did not delve into any self-reflection.

These interviews were relational for me too. After the interview with Emma - one of my own patients – I commented in my field notes that I felt as if I had received a gift. This person had allowed me to see her true frailty and vulnerability and had trusted me with her innermost thoughts.

In my second interview - again a patient for whom I was primary physician – the participant became very emotional, but did not want to stop the interview. I think that having a pre-existing relationship with this adolescent made "entry" easier. There was a comfort in our relationship that allowed him to more freely show his emotions. I was able to discuss with him issues that I would not normally have time in my day-to-day practice to explore and certainly not if his parents were present, as they often were. Seeing the depth of his emotion made the interview especially difficult for me. Seeing his "bottled up" emotion being expressed and talking about his hopes and fears made me as a clinician want to fix it all. I felt that I had failed him in not allowing space or time for him to express his pent up emotion previously. As a researcher I appreciate the time I was able to spend and build relationships with these young people.

Early in Chapter 4 I spoke of the 'power' relationship that I was concerned would harm the interviews and not allow the honesty of the narrative to be revealed. However, my position as a primary physician helped add depth, as

examples in this interview. I touch on this later in the chapter where the relationship adolescents have with hospital staff is so important in building honest communication and trust. This interview highlighted for me that relationship rather than power was important.

In summary, adolescence is an exciting but complex life phase in which individuals transition from children to adults. As adolescents make this transition, they tackle the developmental tasks of identity formation (as discussed in section 1) and separation from their family that will continue to challenge them as they mature into adulthood. Discovering one's identity and figuring out how to relate to one's family as an adult influences the shaping of personalities, influences lifelong relationships, and perhaps even lifestyle choices. These developmental tasks can be challenging at best, and when threatened with illness the adaptation of both the adolescents and their parents may be threatened too. My cohort has shown that they are able to continue safe exploration of the self and express the importance of connectedness. They speak of being able to maintain meaningful relationships with family and friends and that social media provides opportunity to realize these relationships differently. Despite a cancer diagnosis they are able to define life itself and, by so doing preserve hope.

Section 3: Spirituality

Figure 4: Spirituality Theme with Sub-themes

The North American literature has identified critical health events in life as being a form of a spiritual crisis. This is described as a loss of identity leading to fear, chaos and personal disorientation. John Hardwig (2005, p 339)

differentiates between a spiritual crisis rather and a medical crisis; “a spiritual crisis is, a challenge to someone’s fundamental values, commitments and the basic beliefs that have shaped the person’s life”. The mere sharing of their narratives and in describing their medical crisis is already, in essence, disclosing of a spiritual self to me.

Religion and spirituality are different concepts but often intersect. Having a religious belief aligns one with specific beliefs and dogma whereas spirituality is often expressed as something greater than the individual self. To put this chapter into context I have included a brief philosophical discussion in which two schools of thought are described, one a summary of Existentialism and the other, the theory of the spiritual development of adolescents. This thesis is not a debate on the different schools of thought in the philosophy of Existentialism but rather a summary to put into context findings of my study. Later in the chapter I make reference to this concept as it relates to findings in this study.

Existentialism

In the 19th century there was an emerging sense that science and the evolving technological world inhibited individuals from finding purpose or meaning in their lives. Many philosophers are linked to this school of thought; Satre, Heidegger, Kierkegaard and Neitzsche, all, with subtle variation in their beliefs, described the need “to be human”, to find a reason for being and for having free choice in choosing one’s values. The German scholars argued that meaning was threatened by religion. Heidegger (Kaufmann, 1975) described existentialism as the “essence of being human” and “being in time”. His core belief was that by being human, one existed. His thoughts spoke to the authenticity of being oneself. He argued that by having choice is what contributed to living an authentic life and not to be self-deceptive in the way one lived. This was how, he believed, humans brought meaning to life in a world with abnormal influences.

Satre (Kaufmann, 1975) embraced the notion of existentialism but believed that existence preceded meaning. Collectively these scholars introduced the notion that individuals had choice of freedom, an identity, love, a lived experience and death. This “lived experience” is one that is individually expressed but often in a reciprocal relationship with the world and the environment. In the current study this suggests that when an individual struggles with something bigger than “self”, the individual will look for the meaning.

To live this authentic life, one has to be autonomous, be able to reflect and create a life with choices. There is an inherent selfishness in this self-creating which continues during adolescence when self-focus is heightened and reciprocity with the world is seen. Through their own consciousness, human beings are able to determine their meaning of life and thus are able to create their own value and moral structure. Kierkegaard (Kaufmann, 1975) and Neitzsche (Kaufmann, 2013) both spoke of individuals having free choice in their fundamental values and beliefs. In his writings Kierkegaard stated that a “leap of faith is a possible means for an individual to reach a higher stage of existence that transcends and contains both an aesthetic and ethical value of life.” (Fowler 2006, p 34).

Spiritual development

To put into context some of the findings from this study, I would like to include a brief discussion on spiritual development. I have included this discussion here rather than in the literature review as I hope it will bring focus to this chapter and the findings from my cohort. As more scholarly attention is being directed towards the study of spirituality the definitions of what spiritual development really is remains vague. Spirituality, spiritual development and religious development are all well described domains but no consensus can be reached on what these terms actually mean or how they differ (Spiritual handbook). The sentiment in the literature is that to better define these terms may run the risk of inadequately capturing the "richness, complexity and multidimensional nature of spiritual development" (page 6).

Many psychologists and psychoanalysts- including, Freud, Jung, Maslow, Erickson and Fromm - have all contributed to literature on spiritual development in children and adolescents in different ways. In 1964, Erickson (1964) described the transition from the first stage of his developmental model as occurring when the virtue of hope is attained. Hopefulness evolves over time into faith allowing the individual to trust in the universe without evidence. Erickson went on to propose that religion was the institutionalization of this hope. Erickson's stage theory influenced Fowler's faith development theory in which the latter described the integration of one's own identity and a sense of meaning and unity. Differing from Fowler, the European school of thought (Oser and Gmunder, 1991) puts a more religious structure to their theory.

In the 1970's and 80's Fowler, developed a framework for the conceptualization of a "Higher Being" or God and the impact this concept has on values, morals, relationships and the meaning of life. In a book written by James Fowler (1995 Ch. 3), he describes the influence of Kohlberg (moral development), Piaget (cognitive development) and Erik Erickson on the formation of his "Stages of Faith". Fowler himself cautions that to describe the development of faith one has to appreciate the complexity of the person and the context. Despite this complexity Fowler's stages have been challenged for being very rigid and not addressing the uniqueness and individuality of spiritual development. Children and adolescents are enmeshed in multiple and complex influencing factors all shaping their individual development.

In his Faith development theory Fowler labels the first stage 'Primal Faith' and suggests this lasts from infancy to about 2 years of age. In this pre-language stage, trust is the key component and influences the development of attachments and emotional bonds. As these children enter into early childhood they enter the Intuitive-Projective faith stage. This parallels Piaget's preoperational stage and the period which Erickson describes as the stage of autonomy versus shame and doubt. By middle childhood, children are developing operational thinking (Piaget, 2006), more logical and prosaic thinking, and entering the Mythical-Literal stage of Fowler's faith development. In this stage children and young adolescents are learning to manage and interpret strange feelings, emotions and impulses. They do not construct God in personal terms but rather as part of the "cosmic fairness" (2006 p39).

With the emergence of adolescence come bodily, hormonal and sexual changes as well as the emergence of formal operational thinking (Piaget, 2006). These children are able to engage in abstract thought, to reflect on their own thinking and to bring meaning to their thoughts. This corresponds to Fowler's Synthetic-Conventional faith stage where youth form beliefs and values and develop relationships that are dependent on acceptance providing a sense of identity and meaning. During this stage youth lack a sense of objectivity and the ability to develop a viewpoint outside of themselves. It should be understood that these stages are merely descriptors in the literature and not a value judgment. Equally, it is important to understand that adolescents and adults may not reach the later stages of faith but I describe them below for completeness.

The Individuative-Reflective stage is characterized by being able to reflect critically on one's beliefs and values, the struggle with self-identity and establishing a sense of self-worth. This stage of development is described in relation to secular-value systems and seeking answers to the question. "Who am I" represents this stage. Adolescents, young, middle and older adults may operate in this stage.

The Conjunctive Faith stage is characterized by an ability to evaluate multiple perspectives, questioning the paradoxes of religion and an openness to new cultures and worldviews. It is a period in which there is a desire to find new ways to relate to self and others. In cognitive development we see the child evolve from a primary focus on the self to include a wider circle of people. So in the final stage of faith development, Universalizing Faith, we see an increase in the circle of "people who count". During this stage adolescents are concerned with the being as a whole. They develop a passionate belief in peace and the goodness of all creation and a sense that humanity is essentially good. Mahatma Gandhi might epitomize an individual who has reached this stage of faith development.

While some may find limitations with this developmental theory it provides a useful framework with which to describe some of the findings in my research. Stephen King (Nelson 2014), a chaplain at the Seattle Cancer Care Alliance in an article in Medscape Medical News commented that polls and surveys show that in the United States of America, more than 90% of youth found religion somewhat important in their lives. A more secular view was reflected in my study. When participants were asked to define spirituality a typical response was:

"I understand the concept – can't define it." (Basil)

Robin Alfred (2003), in a paper first presented in 2002 at the *1st International Conference on Organisational Spirituality* in England, stated that: "Attempting to define spirituality is, in some ways, attempting to name the unnameable and to define the indefinable, to use words to describe that which lives between us and within us. It is therefore an exercise in approximation." The definition in Wikipedia is as follows: "Modern spirituality is centred on the deepest values and meanings by which people live. This definition embraces the idea of an

ultimate or an alleged immaterial reality. It envisions an inner path enabling a person to discover the essence of his/her being."

Many people believe organized religion holds the only keys to unlocking life's purposes and lessons. For these people dogma plays a critical role in their everyday life and existence. Richard Rorty (1981) in his book, *Philosophy and the Mirror of Nature,* developed the notion of 'edifying philosophy" which gets rid of any systemic absolute knowledge in favour of the pragmatic and that which "builds up" or edifies the human experience through dialogue. From this practical philosophy emerges the expression of practical spirituality which approximates the view expressed by the participants: a process of making sense of the here-and-now and a process of becoming more self-aware and a whole person. Practical Spirituality is about one's personal growth and development. This is expressed in relationships with parents and friends and in the need for school and for acceptance. These young participants are able to interpret their experience through images, values and beliefs.

In Wilf McSherry's work (2012, p118) he defines spirituality as being "universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity." (In my interviews my attempts to get to the core of each of the participants' spirituality reflected this individual and unique quality. There was no universal definition or any expression of spirituality that I could identify as novel. These youths often equated spirituality with religion, but were very clear in their articulation of the "unique capacity" of the individual.

"I'm not a spiritual person at all …umm… don't have any religious beliefs. I'm whatever I want to be. It depends on my choice so I'm free to choose to be better. It's just human nature to do better or want to be something, have goals, wanna achieve them, you wanna be happy and feel these things." (Sue)

For me to contextualize the ideas expressed by the youth on spirituality it was easier to think more philosophically and embrace the school of existential thought.

Existential thought

For some participants when asked about spirituality, they denied being religious but proceeded universally to describe existentialism. When using this sweeping statement, I mean to express their thoughts as defining a purpose for their lives, a feeling of being connected and the importance of meaningful relationships that made them whole. This expression of wholeness was clearly described.

To highlight my approach in describing the ideas expressed by the youth as existential I would like to consider the opposite. Existential indifference is a term in the psychology literature (Schnell, 2010) described as a state of low meaningfulness. People who are existentially indifferent show little or no

interest in all sources of meaning, self-knowledge, connectedness or spirituality. The youth interviewed in this study showed no evidence of this indifference.

I was just trying to think about what this has meant to me… it's hard to explain, like it's hard to get out. A lot of things… like, this has changed me completely. Like this whole experience. I look at life in a whole different perspective. I'm a lot more grateful. Everyday is a gift. I wouldn't be the person I am today if this didn't happen." (Emma)

"I mean everybody has spirituality. Some people embrace it some don't. I just kinda go with it. Spirituality is just part of who you are. It's just how you are. It's like part of your attitude, part of your behavior it has influence on everything. It's what makes you special." (Linda)

"Not really religious or anything like that, I don't go to church that much or anything so this is not part of me. It seems that getting through this and being normal at the end is important to me. Being more human." (Basil)

"The part of me that knows I'll be stronger. It kinda makes me think if I can do this I can do anything. I can go outside my comfort zone." (Diane)

"I think of more logical reasons as why things happen the way they do and I give reason for everything and I have to give a reason for everything I do so there is always logic behind everything." (Linda)

"It helps a little bit because you know we can't contact this higher power, some people believe they can as in speaking to God and you know I think this higher power puts you in a place that you need to be, when you need to be there so I think, I'm here for a reason, I'm just not sure what it is yet." (Linda)

"I feel like there's a new me, like the old me is like gone. Like I feel like I have a new life, so like I was reborn or something. I have a new person, new person." (Queenie)

"I think of my spirit as confident and cheerful so I would just say, 'cause I don't know how to explain spirituality. I feel like …in my meaning it's like personality but in a spiritual way (laughs)." (Queenie)

Formal belief

Adolescents are positively influenced by spiritual and cultural values. That religious issues are important to many adolescents is illustrated by a recent study of youth aged 11 to 25, in which more than 85% said that they believed in God, and more than 90% asserted that religion was at least somewhat important in their lives (Holder et al., 2000). Specifically, the National Longitudinal Study on Adolescent Health found that youth whose families place importance on church attendance and prayer are less likely to become involved with substance abuse, such as alcohol and recreational drugs compared to those whose families do not place importance on church attendance and prayer

(Resnick et al., 1997). Adolescents who attach greater importance to religion also reported less involvement in sexual activity (Holder et al., 2000).

Four participants reported having an organized belief system. Three participants reported a Catholic faith, with 2 of these participating in church youth groups with regular support from their religious leader. One reported being Evangelical and also involved in a youth group. These participants equated spirituality with religion and described their youth groups and the active involvement in them as their spirituality.

"Yeah I go to church sometimes but not every Sunday. I pray when I can't sleep. This helps me calm down. After my mother died my brother and I wanted to go to church. I was so sad that I got interested and I started going to church more and pray more privately but I always forgot to do grace (laughs)." (Jane)

"I think in order to heal well you have to have a positive outlook. 'Cause I think people really say I'm sick, I may not be better and my body not well but my soul is." (Jane)

"So I just wanted to prove to them, and prove to myself that I can do it and I , umm, I…I can beat this cancer so I prayed every night and that helped a lot. I prayed… and everyone's love and support." (Queenie)

"…and when I started to get scared I felt like, umm, Jesus' presence, God's presence and felt like He was hugging me and telling me 'don't give up' and that just gave me lots of courage and strength to go on 'cause He told me not to give up, so …you know." (Queenie)

"'Cause I knew, I had faith and I knew that, umm, I knew that if I quitted then I really actually had no hope." (Queenie)

In summary, the youth interviewed spoke about both their religious and spiritual worlds.
Despite having difficulty in defining spirituality for themselves, they were very eruditely able to express personal trait or a state in which they showed their own response to existential questioning. It is this either religious or spiritual world that provides a paradigm that addresses these questions and leads to hope and acceptance. Helping make sense of suffering and illness and hence has an impact on resilience.

Section 4: Creativity

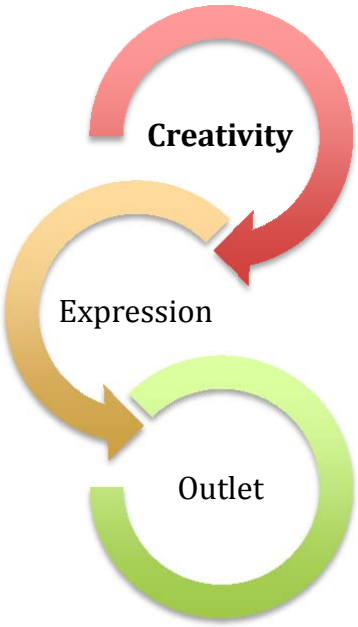


Figure 5: Creativity and Sub-themes

Youth and creativity have long been interwoven; as Samuel Johnson once said, "Youth is the time of enterprise and hope." This theme emerged consistently in the interviews and was unexpected. Creativity was expressed in listening to music, composing music, writing poetry and drawing. In some instances this appeared to be a means of "hiding".

"Music helps a lot. If there wasn't music I don't know what I would do because whenever I'm having a bad day I just tune out the world and… listen to upbeat music." (Emma)

"..I find just putting headphones on… I go to where I'm happy." (Emma)

Other participants described their creativity as a form of self-expression and emotional release:

"I used to write a lot of poetry and I'd write a lot of happy…even when I was in this dark place I would write something happy. I'd write about my favorite things. I'd write about, you know, fall colors and how pretty and…" (Linda)

"My favorite form of showing people my feelings is through art." (Jane)

"Either a good cry or… writing… it was a little bit of an escape, like therapeutic of some sort." (Queenie)

"I actually stopped writing at that point because, well a lot of the time I was tired and I thought, you know, maybe when this is done I'll write a book but right now

I just want to experience each day as it is and I wanna keep reflecting and …" (Diane)

Creative expression has been used widely in paediatric medicine as a means of therapy including art, music and play therapy. This offers the patient a creative outlet and an expression of self. In some settings this is not just therapeutic but may in fact be diagnostic as in the role of play therapy in psychiatric illness. Malchiodi (1999) eloquently describes how art therapy is used with children who have experienced sexual and domestic violence as a means to express themselves through art and give voice to their stress through their drawings. She also points out that this form of therapy requires specialized training in the interpretation of the child's physical and psychosocial expression in their art.

Not only may art therapy be viewed as a form of healing, but Mimi Farrelly-Hansen (2001) argues that art making is inherently spiritual. This creative expression as a spiritual expression is an important part of the treatment and the healing. Malchiodi (1999) also claims that engagement in an art form helps the children "transform and transcend" and therefore heal.

Different forms of art allow the child to communicate their inner feelings and also offer therapists an insight into the child's developing maturity or regression. Developmental theorists have shown us that during adolescence children are better able to understand abstract concepts and to form judgments. As adolescents mature through developmental stages they often become self-absorbed, dependent on peers and may withdraw from their parents. Teens frequently hide away, withdraw from parents and seek out artistic ways to express themselves, so poetry and song writing is not an unusual developmental milestone. As Riley (2001) notes, "drawing, or making marks, is in tune with adolescents' development, as evidenced by the tagging and graffiti that is abundant in many cities". It is hard to restrain an adolescent's urge to "make their mark".

During the interviews, while the participants spoke of their art, a deeper interpretation was not expressed. They described this creative side of themselves as a part of who they are and a very matter-of-fact way. As I was not sure what would emerge in the interviews, actual examples were not provided. However, after the interview a number of the children chose to share their art with me. I have annotated these for clarification and to provide context, but I have *not* tried in any way to interpret or dissect the art in any therapeutic way. If comments were made about the significance of particular items during the actual interviews I have included this in italics. In the following pages I provide some examples of these with some context.

The following poem was shared, with permission, by Timothy (15). This was a profoundly intelligent boy and deeply insightful. When reading the poem knowing he had a poor prognostic brain tumour is important. I see an outlet for his fear, the questioning and, at least in his poem, acceptance.

Nirvana

A cogwheel, like clockwork/Spins in my head
My brains inner rhythem/Needs to be fed
Sapping my life-force/Logic has fled
Painfully waiting/When will I be dead?
The cogwheel, like clockwork/Still spins in my head
The Ether, the Void/Is empty and still
I've been waiting/Waiting until
The moment of silence/Of silence and bliss
My memory has failed me/Replaced by a mist
The Ether, this Void/Has filled me with fear
My heart is still pounding/My brain isn't clear
The Ether, this Void/Has rendered me still
...I have no memories/Have I been killed?
I felt as if sleeping/But now I have waked
Now I feel pure; I used to be fake
The light now surrounds me/Has my vision failed?
Gravity impounds me/My mind is derailed!
Heaven has found me/Look what it has brought
Nirvana surrounds me/This is what I sought
I have been found/The path forward is clear
I am now finished/I have no fear

Another poem by Timothy; grappling with existential questioning. He explores all that he is.

I am from wilderness
From fronds, ferns and fungus
From the rain on the trees for millennia past
I am from moss-covered boulders and bridges
Of single plank cedar, spanning small rivers
That flow out of forests to smooth pebble beaches
While two tired salmon struggle upstream.

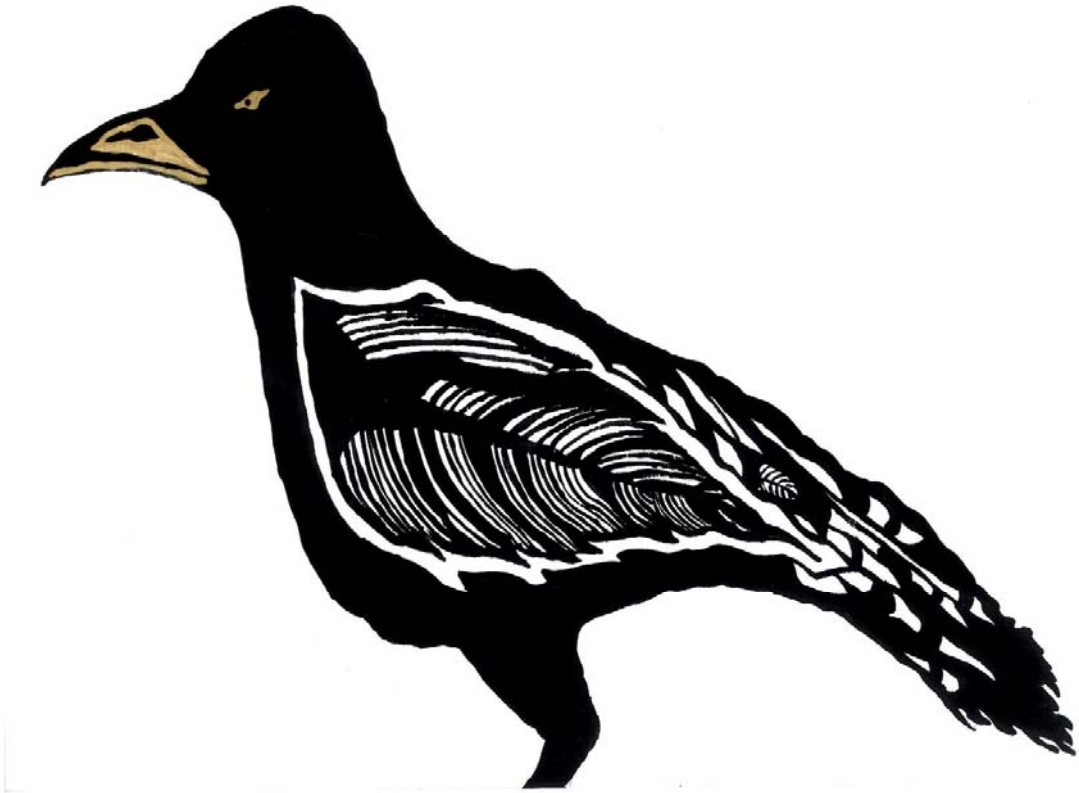
I am from city
From 'info' and 'wi-fi'
From rocking horse people and radical thoughts
I'm from authors and readers
From new thoughts and new music and new ways to live
From art on the streets and from art on the buildings.

I am from ocean
From wind on the water
I am from dinghies and cutters
Not just fiberglass and Dacron
But from oak, elm and cotton!
From ropes and oiled tackles
From Heave! and Gybe Ho!
I'm from low *or* high water, cause anytime is good for me.

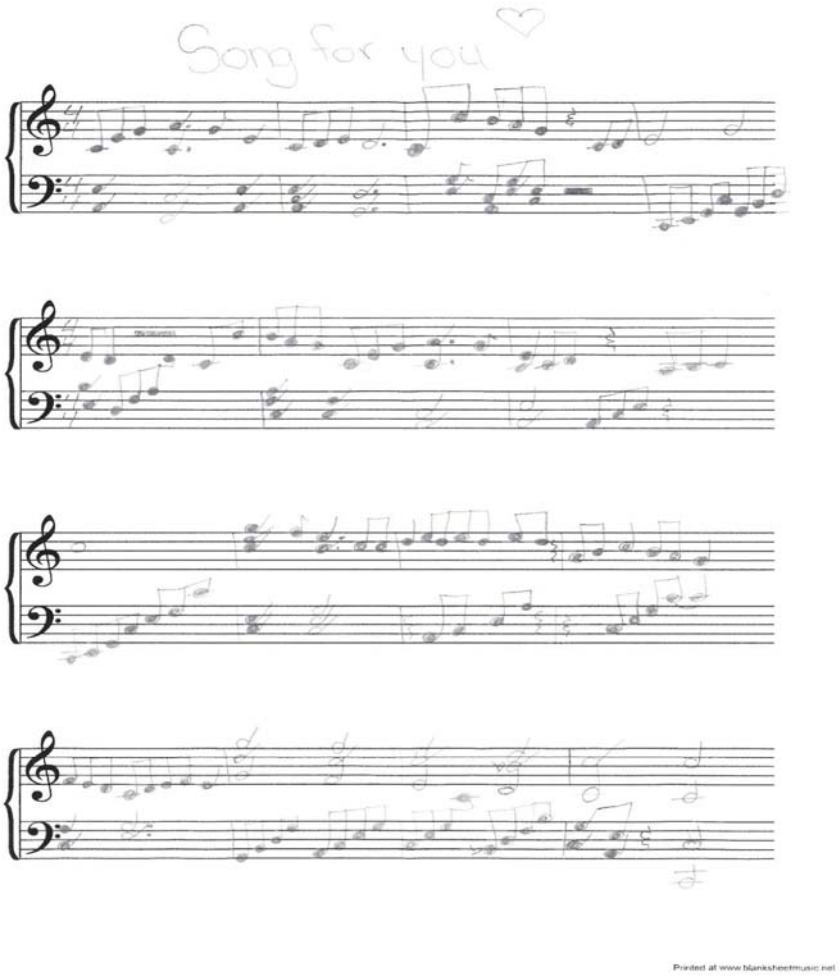
I'm not just from people, from places, from things
I'm from ideas, from my interpretations
From discussion of problems
From different solutions
From groups of like-minded thinkers
Cooperating to reach a goal
I am from creativity, imagination and ingenuity
I am from many, from all who shared their story.
I am from *you*

Sue started drawing crows once she was diagnosed. These were black crows, some in cages and some free; always painted back and cages gold.

“I put them all over my room. I felt caged and wanted to be free like the birds” (Sue)



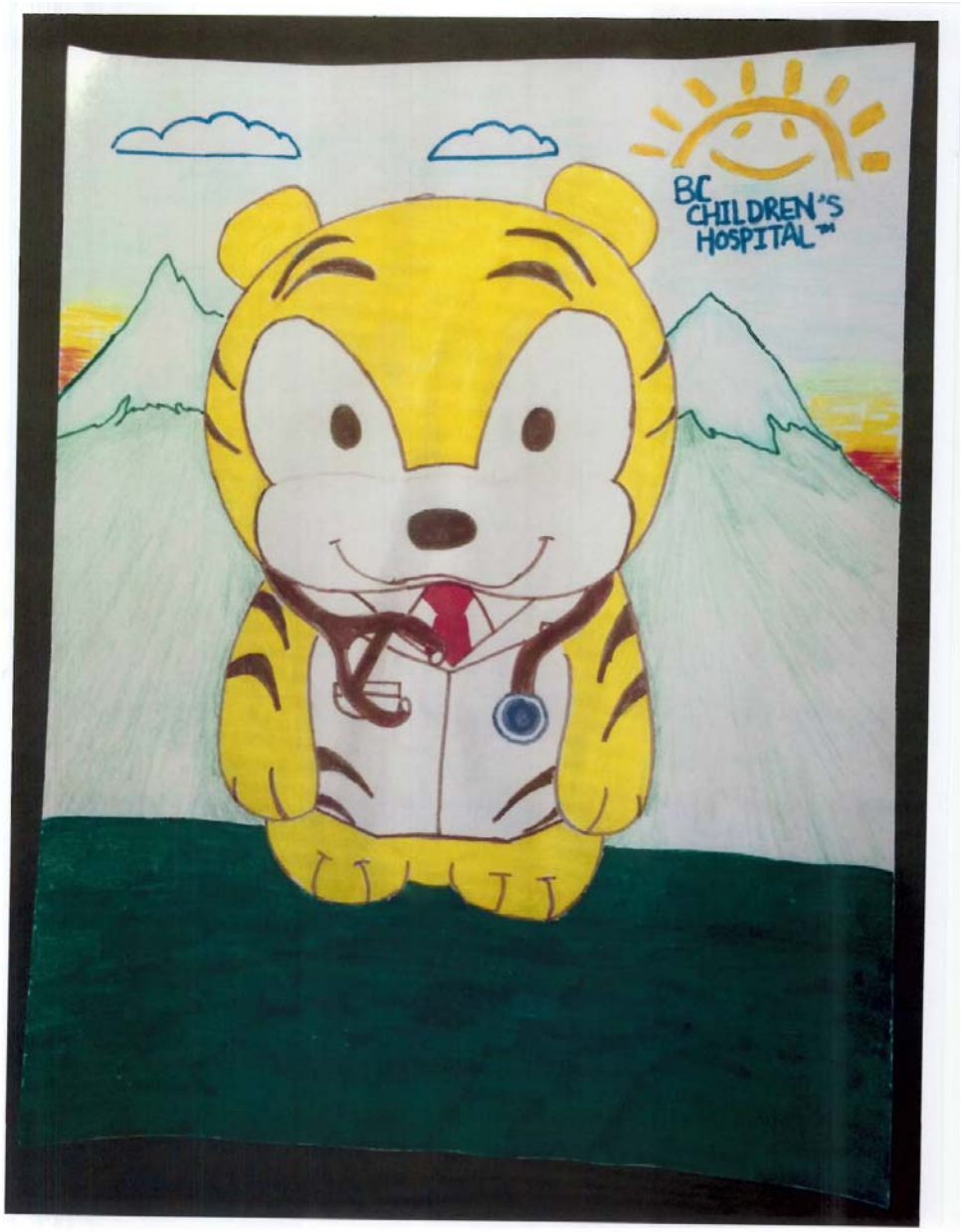
Karen, a gifted pianist, composed the following song and had one bar tattooed on her wrist.



Jane drew angels, all ethereal and explained that they were her guardian angel. She had them all over her hospital room and spent hours drawing and painting. She had lost her mother and stated: "*My mother is my guardian angel."*

Marc drew a painting of his favourite stuffed toy and chose to depict the toy as a doctor. He had a "*fear of white coats"* that he disclosed in his interview and explained how he had to work hard at overcoming the fear and gaining trust in his care team.

"At first I think that day in emergency when Dr…. came in and he looked really scary and looked very serious, but I think it helps because doctors here don't wear white coats and it kind of, when I came in, it doesn't seem like a hospital much."



Karen composed the song below in which she refers to her chemotherapy (the white), and her isolation. In reading the lyrics it is important to know that she was diagnosed with an osteogenic sarcoma and underwent an amputation. The amputation is never explicitly referred to but intimated in the description of "what they're actually doing to me" the fear, sadness and inner turmoil are clearly identified.

The halls were cold and nobody occupied them but us, and how could I forget your beautiful blues eyes that October night
My skin is black and blue and I am tired of missing you can you hold on just a little longer I am pale and out of breathe, I don't have energy to say the rest of the things you need to hear like
One more time and I'll be fine but that may just be a lie as the red fills up my veins and the white washes it away turn away so you cannot see what they're really doing to me I am sorry but you will have to leave like I did but it's just for now
Taking each day as it comes because I know I'm not alone even though you're gone and that smiling face is what makes me feel okay when I am the farthest from
They said rate the pain, doing everything they can but it was out of their hands
One more time and I'll be fine but that may just be a lie as the red fills up my veins and the white washes it away turn away so you cannot see what they're really doing to me I am sorry but you will have to leave like I did but it's just for now
The lady in the black jacket always seemed to know what to do her hands were cold and they remind me of you
One more time and I'll be fine but that may just be a lie as the red fills up my veins and the white washes it away turn away so you cannot see what they're really doing to me I am sorry but you will have to leave like I did and it's all over now

The following is an excerpt from another of Karen's poems where she embraces her questions. This shows a framework for understanding life, her life, her isolation, her suffering. This poem shows her asking her ultimate existential questions and her rising above adversity, her resiliency.

ONLY YESTERDAY (EXCERPT BY KAREN)

SOMETIMES IT FEELS LIKE ONLY YESTERDAY
THAT I WAS WISHING FOR THE END

SOMETIMES IT FEELS LIKE ONLY YESTERDAY,
THAT I COULDN'T GET OUT OF BED, DANCE, OR PLAY.

SOMETIMES IT FEELS LIKE ONLY YESTERDAY,
WHEN PEOPLE WOULD LOOK AT ME WITH PITY IN THEIR EYES,
WHEN WHEREVER I WOULD GO PEOPLE WOULD ALWAYS STARE
AND WONDER WHY.

WHY DID I HAVE TO BE IN THAT STUPID CHAIR?
OR WHY DID I HAVE TO LOSE ALL MY DAMN HAIR?

WHY DID I HAVE TO GO THROUGH ALL THAT PAIN?
AND GO THROUGH ALL THOSE STARES?

WHY WAS IT ME?
IT JUST WASN'T FAIR.

I USED TO WANT TO FORGET,
FORGET ABOUT THE PAIN.

FORGET ABOUT THE TORTURE I WENT THROUGH
THAT NO ONE ELSE MY AGE HAD TO DO.

I STILL HAVE QUESTIONS,
AND I STILL DON'T UNDERSTAND IT ALL.

BUT I AM WHO I AM,
BECAUSE, OF WHAT I'VE DONE.

I DID IT ALL

I SURVIVED,
I MADE IT WHERE I AM TODAY.
SOMETIMES IT FEELS LIKE ONLY YESTERDAY.

For some participants their artistic expressions were too private to share, but I am touched by and grateful for all the pieces that have been shared to provide support for this theme in the study

Section 5: Communication

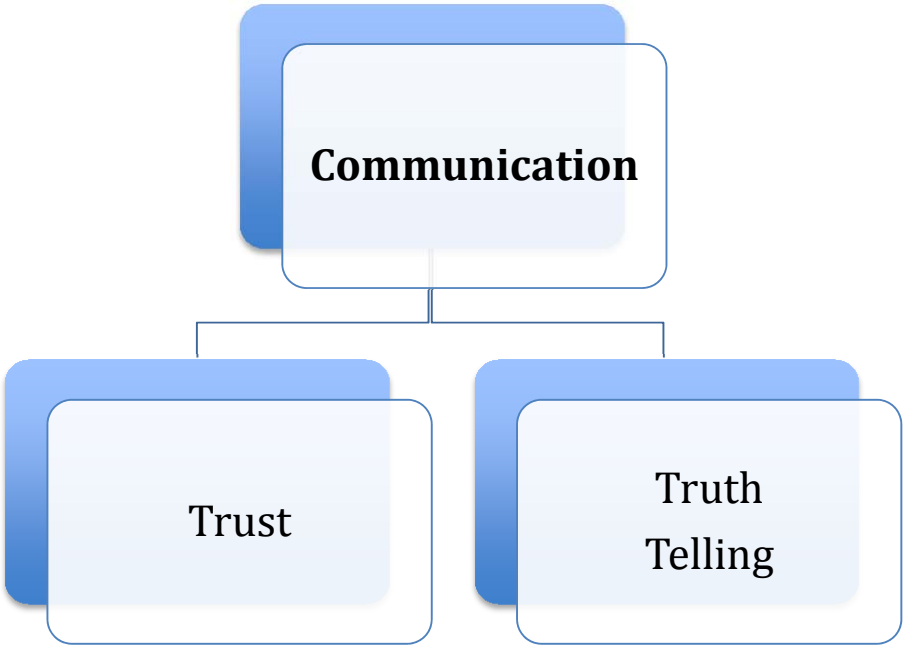


Figure 6: Communication and Sub-themes

Moral development progresses in tandem with the mental and emotional maturity of the youth. With this progression the youths' understanding of right and wrong becomes more sophisticated and nuanced. This has been well described by both Piaget and Kohlberg. Kohlberg goes further in suggesting that some youth may make moral decisions with consideration of ethical principles and not just rules and laws while others will remain rigid in their moral thoughts.

As this moral development progresses the youth may become more challenging of authority and develop their own unique set of values and beliefs.

Cognitively, adolescents' thinking skills rapidly advance as they enter Piaget's stage of formal operations. They are now able to think in abstract terms, understand illness, consequences and death. At this point adolescents are able to critically analyse problems in a more logical and scientific manner. They can store scientific information and retrieve it when required. Research has shown that the complete development of the frontal lobe is not complete until late adolescence to mid adulthood. The frontal lobe enables humans to inhibit emotional impulses by using rational thought to override these emotional impulses. This incomplete development in adolescents can lead to difficulty in making wise and thoughtful decisions in the presence of powerful emotional pressures. This may make discussions around transplant, intense chemotherapy, relapse and dying more challenging with adolescents.

In the resilience literature, the 7C's of resilience are described (Ginsburg, 2015) with Control and Competence being two of the C's. The other five are: Confidence, Connection, Character, Contribution and Coping. For the teen to be in control and be competent in their cancer experience they need to be part of the discussion around their illness and treatment; to provide their assent (or consent in some cases), for their treatment, and to feel empowered by their decisions with a sense of ownership of their treatment. Practically, some teens may be too ill to be part of an initial disclosure meeting, but a time may arrive when they will be receptive to receive information and knowledge about their disease.

Javier Kane (2001) says that competence in treatment must never be apart from compassionate care. With reassurance of relief of pain and treatment of any distressing symptoms, the detailed treatment plan can be discussed, including clinical trials. All patients want reassurance and support and to know they will not be abandoned in their treatment and care. They want the truth about pain, about the future and, with this information, the opportunity to articulate their fears and needs. Adolescents may not be able to make the wisest decisions in the time of crisis, but they can give voice to their fears, sense of loss and wishes regarding their therapy.

The challenge is always to provide truthful information, especially in poor prognostic situations, and still maintain hope for the teen. Eric Kodish (1995) very succinctly describes the need to balance the obligation to be honest with an equally important duty to cultivate hope. He suggests, "…hope should not be entirely dismissed, for it is one major mode by which people anticipate the future" (1995, p1881). In a study by Kuttner (2006), she showed that in a population of 22, 100% of patients wanted the doctor to be honest and 91% also wanted the doctor to be optimistic. What this optimism looked like was elucidated by Hagerty (2005); offering up-to-date therapy, demonstrating knowledge of the disease and acknowledging the patient as an individual. Adolescents desire to be listened to by their care providers (Carr-Gregg, 1997) and want to be included in designing their care plan. Re-establishing a sense of control in some aspects of their life enhances their willingness to become engaged and to begin to take ownership of their treatment. For example, if given control on when they want visitors, when they are given up-to-date and truthful information about their condition, it facilitates coping with the uncertainty of their illness. This inclusion and need for truth was expressed by the teens in different ways. There was the feeling that they wanted this control, as articulated by a 17 year old girl:

"I have to just realize that I can't always depend on other people to make my life perfect. There is nothing that I can't hope for, no one else to do it for me but I've got to do it myself." (Sue)

She wanted the ability of self-control, the belief in herself and she could only do this with knowing all the truth.

"And they said I had cancer and everything. And then I started to kinda tear up and they both started to cry with me and then they just like…"It's okay we're

gonna all get through this. You can do it". So I, umm, I think that gave me hope." (Queenie)

Again, the truth giving rise to hope but also and Queenie infers the team effort and family support. Jane espouses the same sentiments.

"I think just knowing that everyone is doing the best as they can like doctors and nurses. I know that it's the health care they have here is really good like the best and good options for therapy and like that really gives me hope." (Jane)

"Having all the information, the truth and no surprises, that's what gives me hope." (Steve)

"The number one reason why giving up isn't no option for me. Imagine if I just gave up? I wouldn't never know I could have a second chance." (Emma)

In times of uncertainty and times of feeling a "loss of control", hopelessness becomes more overtly manifest. Many of my patients with a serious illness experience a profound loss of predictability and control, which I believe, is an inherent component of the hope experience.

"When people ask me how I stay strong and optimistic I don't really know how to answer. Of course I have books and movie days in order to take my mind off things but fear is something I have learnt to listen to. I think that this goes hand in hand with hope. Why else would I despair unless I was afraid of losing the fight? It's just another reason to fight." (Steve)

"…for the diagnosis meeting I wasn't feeling up to going so they went and had the meeting with my parents and came back and told me. I was numb for about 10 minutes but a combination of the drugs and everything I was wondering was wrong for a few days. It's just a passive experience. I just remember crying when I first heard, I don't really remember looking for more information or something. I just want to know now." (Rod)

Trust

Trust in the care team and an understanding of the present is an important aspect of care for all patients, not just teens.

Li (2007) suggests that the conversations care providers have with patients should set the stage for exploration. This is the time to ask what it is that patients hope for, to provide clarity around when hope of healing is real and when it is not, and to hear their goals. This conversation should include discussion around the disease and side effects, but should be so much more. I would like to suggest that a caregiver - patient relationship in which respect and honesty are shown enables the teen to feel safe to explore existential issues.

Teens who feel they have lost control feel isolated and misunderstood, that they are not taken seriously and that nothing they say is deemed important.

Participants in my study demonstrated trust in their care team and a belief that they were receiving the best care.

"I think just knowing that everyone is doing the best as they can like doctors and nurses. I know that it's the health care they have here is really good like the best and good options for therapy and like, that really gives me hope"(Jane)

Others really want control and involvement:

"Having all the information, the truth and no surprises, that's what gives me hope." (Steve)

This study used narratives to extract themes related to hope. The notion of unrealistic hope had not been explored but a paper on hope would not be complete if I did not at least make mention of the concept. I understand false hope to be another person's hope that doesn't align with my own. In the case of this study, I would understand unrealistic hope to be a misalignment between the patient's hope and my own as a caregiver. This remains a value judgment, and who decides what realistic hope is for a patient?

In the literature there is a strong case made that individuals diagnosed with a serious or terminal illness, and who show determination to live and remain very hopeful are often seen as being in denial or not accepting reality (Hinds, 1988). The assumption here is that health care professionals are in the best position to distinguish between realistic and unrealistic hope within the context of the illness (Bruera and Nekolaichuk, 1998).

Summary

In this chapter I have shared narratives of adolescents diagnosed with cancer. I have tried to use their voice to construct a framework of hope and meaning as they live with their illness. I have situated the interpretation within the context of the developing adolescent as they leave childhood and enter adulthood. Through their words I have explored the impact of serious illness and the reflection it has allowed them to share with me. From these narratives five themes emerged that illustrate how these adolescents' find meaning in the midst of illness. These broad themes include the cancer experience, relationships, spirituality, creativity and communication.

In the next and final chapter I will summarize my thesis and discuss some of the limitations of the study, and suggest implications for practice and potential future research.

"Today I still ask questions
And I still don't understand it all
But today I am who I am
Because of what I've done"

Adolescent Patient

Chapter 5: Summary and Reflection

Introduction

In this final chapter I will pull together all the threads of my thesis and add more of my personal reflection. I will present some of the limitations of this study and possible implications for practice and for future research.

Thesis summary

This is a qualitative study exploring the lived cancer experience of 13 young cancer patients with a focus on how they find the meaning in their lives when diagnosed with cancer and how hope is structured for them as they traverse their illness journey. Chronic illness - and especially cancer with its real threat of death - presents a crisis for patients as it confronts them with an "awareness of the possibilities for the future that are going to be lost" (Hardwig, 2005). I wanted to try to understand how adolescents make sense of their lives when faced with a potentially terminal disease, when faced with their own mortality and what factors support their coping and resilience.

I wanted to explore these themes within the context of adolescence and the complexity of developmental life stages that accompany this period of life. Although philosophers and theorists more experienced that I have been asking the same question for years, my clinical experience has shown me that these adolescents, even when faced with death, have the capacity to find an inner strength that amazes us all. This thesis applies theory and practical knowledge to interviews with adolescents and explores the search for meaning in the midst of a critical life event. It is this quality of inner strength that most intrigued me, and I wanted to identify the factors that contribute to this coping mechanism, in the hope that this would allow us as clinicians to potentially empower it more.

These adolescents shared their narratives with me in the context of this research and offered thoughtful insight. This narrative methodology was important as it captured verbatim the thoughts of the participants and allowed me to interpret between the lines, to decipher underlying themes, and to identify patterns across the group. This process provided participants with an opportunity to share as much as they felt comfortable, and gave them permission to be vulnerable. When asked to reflect on their illness and diagnosis five themes emerged. In no order of importance these were: the experience of being diagnosed with cancer, the value of relationships, spirituality, creativity and open and honest communication.

The experience of being diagnosed with cancer gave the adolescents the opportunity to reflect on “who they are and their sense of identity”. In many cases the identity they reflected was one not entirely wrapped up in their status as a cancer patient. They were able to present themselves as multidimensional with other contextual aspects of their environment defining their identity. The literature portrays adolescence as a period of natural development during which this search for self normally occurs, and for the adolescents in this study this certainly emerged as a common theme. In his work on self-identity in children and adolescents Berzowski (1983) showed that in girls confronted with a crisis matured earlier than other girls, while boys confronted with a crisis matured more slowly than their peers. My sample size is likely too small for me to detect either pattern, but this was not a trend that emerged in my research. While the participants in this study conformed to the expected milestones outlined by the developmental theorists, they showed an enhanced maturity. Themes of self-esteem and self-actualization were clearly noted in the participants and no regression was noted in this cohort. Participants articulated that the diagnosis itself provided a source of meaning in their lives. These adolescents did not speak of stigmatization or a spoilt identity as described by Erving Goffman (1986, p 3) but rather expressed a sense of feeling special or chosen, and observed that the diagnosis had given them an appreciation for life they had not had before.

This notion of being special reflects the normal adolescent development trajectory. In the early teen period, adolescents go through a period of rapid growth and experience significant physical changes. Coupled with this, the ability to engage in abstract thought causes adolescents to wonder what others think of them, and whether all share a common view about the adolescent. This belief that everyone is focused on them leads to a sense that they are special or unique, and has been termed the “personal fable” (Elkind, 1967). With this concept comes the belief that the adolescent is so special that nothing bad will happen to them and they will not suffer. Bad things happening are not part of their image or fable.

In his book *The Anatomy of Hope* Jerome Groopman says (2005, p81), “To hope under the most extreme circumstances is an act of defiance that permits a person to live his life on his own terms. It is part of the human spirit to endure and give a miracle a chance to happen.” While the adolescents in my cohort did not express an expectation of such a “miracle” they certainly conveyed a strong sense of endurance and hope.

Humans are social creatures and most thrive on having meaningful relationships. The resilience literature (Masten, 2001) speaks very clearly about how connectedness is such a protective factor. This sense of connectedness was strongly expressed in my cohort and these relational elements provided another significant dimension of hope. Having meaningful relationships was essential to their well-being and influenced how they expressed hope in their future. This hope was expressed in relation to significant people in their lives including parents and friends. The relationships patients have with others and the context within which these relationships are formed and played out can significantly influence what they hope for as well as whether they are able to hope or not.

A strong, positive mother-adolescent relationship was evident in my cohort. This has previously been described in the literature as being associated with resilience among youth (Mason, Cauce, Gonzales, & Hiraga, 1994). However, strong relationships with other family members such as, siblings and extended family did not emerge as a significant factor in this study. This may in fact be a limitation of this study as the other relationships were not explored more fully. In the paediatric setting parents are encouraged to stay with their children during hospital admissions and it tends to be mothers that serve in this role and this may reflect why the mother-adolescent relationship was more talked about. Relationships with the health care team also did not appear significant in this study.

One theme that emerged consistently across the sample was the role that school played in providing a context of normality and a source of hope for these adolescents. School, was described as providing participants with a sense of belonging; it was seen as a place for shared activity with peers and where they shared a sense of responsibility. Whereas many adolescents endure school, because of their cancer crisis the adolescents in my study longed to go back to school because it was where their friends and social relationships were. There was a sense that attending school would enable them to rediscover a part of themselves that they had lost as a result of illness. The meaning the adolescents place on school remains complex and the return to school not merely signifying being normal again but perhaps attached to yet another function being taken away and serving as a symbol for lack of normalcy.

Michael Bury (1982, p 167) described this disruption of everyday life in patients with chronic illness that he calls “biographical disruption” and like the adults with chronic illness a desire to return to normalcy was described by these participants. For me this desire to return to school also demonstrates a shift in values towards something more concrete and practical. It seems that not going to school forces the youth to reflect on what they value and this leads to a discovery of what is meaningful in their lives. In his work *Radical Hermeneutics*, Caputo (1987) a self-described “weak theologian” characterizes this shifting of beliefs as a discovery of meaning.

While not a surprising finding, the central role of school as a source of purpose and meaning for these adolescents really challenges the way we practice as clinicians. During chemotherapy treatment - and certainly post bone marrow transplant - these patients have very suppressed immune systems. Traditionally we have therefore discouraged patients from being in crowds or attending school where they could be exposed to infections necessitating a return to hospital for treatment of fever. Currently we would recommend a tutor before we would recommend attending school. Perhaps this dogma needs to be challenged in light of the significance school plays in sustaining hope for these adolescents? Safety of patients’ remains paramount, but since it appears that adolescents view school as so important, and the social aspect of school commonly serves as a vehicle for self-worth and hope it may be important both to find ways to accomplish safety and to sustain hope.

Participants in my study who had a pre-existing formal faith described their religious belief as providing an important source of their hope and a way to

define the meaning of their illness. Fritz Oser, a Swiss psychologist and theorist, defined faith development similarly to Fowler but with more focus on religiosity and less age restriction on the stages of attainment of this religiosity. His stages of development were non-age specific and more spiral in their religious development. In his model stage 3 is defined as one in which the Ultimate Being, if it exists, inhabits a domain that is apart from the world, human beings are seen as being responsible for their own life, and external authority is rejected. In Stage 4, life is understood to be possible and have meaning only through the Ultimate Being. Freedom of the human being is related to a Divine plan that underlies life events. (Oser, 1994)

Of the few participants in my study who spoke of religion, most described a belief in an Ultimate Being, coherent with either Oser's stages 3 or 4, with perhaps a tendency towards stage 4. My participants described a belief in God as both real for them, and a source of rewards and purpose in their lives, but also outside the living world. They could acknowledge a relationship where God is not really concerned with their specific everyday frailties.

The participants who did not express a religious affiliation collectively described a meaning for life that was referenced in the future; being cured, graduating and surviving. With this belief in the future came a sense of awe or significance in a life bigger than the self. They expressed a spirituality that spoke to uniqueness and purpose - a sense of existing in the world and with a very clear purpose. Satre in his distinction of "*etre-en-soi*" (being in itself) and "*pour-soi*" (being for), provides a useful framing for what these youth expressed. The future was characterized as having value through "being for" relationships, for art, for goals, for dreams and for hopes. This might be understood as *Spiritus,* which in Latin means the breath, courage, vigour and soul. It is this that I believe these young participants articulated in their narratives even though they did not use the term spirituality.

This spirituality was what sustained their emotional and mental wellness, reduced anxiety and guilt, enriched relationships and actively promoted authenticity. This was characterised by compassion, openness to truth, and a visible commitment to the value of difference and interdependence with the earth and the wider human family. This spirituality, I believe, expressed by these participants is a conscious embrace of the inner need for meaning and purpose, prompted by a crisis and simply engaging with the ultimate existential questions that confronted their human condition. Life-threatening illness, intense suffering and fear of death are all circumstances in which individuals are driven to seek meaning, comfort and help and a conscious and articulated spirituality is frequently born in such moments. Perhaps summed up in a quote by Viktor Frankl (1964, p56-57): "*The salvation of man is through love and in love.* I understood how a man who has nothing left in this world still may know bliss, be it only for a brief moment, in the contemplation of his beloved. In a position of utter desolation, when man cannot express himself in positive action, when his only achievement may consist in enduring his sufferings in the right way—an honourable way—in such a position man can, through loving contemplation of the image he carries of his beloved, achieve fulfilment. For the first time in my life I was able to understand the meaning of the words, 'The

angels are lost in perpetual contemplation of an infinite glory."

One may argue that this described spirituality is akin to what personality theorists like Freud, Jung and Adler refer to as s*tates*; that is beliefs, attitudes, feelings and behaviours that are strongly linked to the immediate circumstance and contextual demands and are temporary and situational (Carver, 1982). That this could be linked to circumstance that at best is a deeper discovery of one's identity, and at worst a critical crutch to help one through an otherwise devastating time. Regardless of whether spirituality is linked to identity (akin to a trait) or to circumstance (akin to a state), it still provides a coherent frame or paradigm for understanding and responding to the immediate moment. It defines and informs the lens through which the individual engages each moment. It is the platform from which one starts, the impetus for some kind of action, the sustained momentum for ongoing engagement, and the guard rails that shape the direction and perimeters of the ongoing engagement with unfolding events. As such I believe that the spirituality expressed by these participants is a key component of resiliency and self-efficacy.

Perhaps the term *spirituality* could be better interpreted by a term that embraces their understanding of their world; an understanding of their lives, illness, suffering and even death. These participants had a keener ability to express this dimension, call it spirituality, adding to their resilience and self-efficacy. This spirituality is triggered by existential questions and the emergence of their own response to the ultimate existential questions. Personal faith, or spirituality, can be either a 'trait' or a 'state' but either way it provides a paradigm that addresses the ultimate existential questions and leads to hope. These adolescents were able with this hope to find peace and even acceptance. Helping to make sense of suffering, and as such an individual's personal faith (spirituality) has an impact on resilience and self-efficacy.

The creative expression disclosed by all the participants was a fascinating theme that emerged. The fact that these adolescents were creative was not a surprise as, developmentally, this is the age of self-expression, but the richness of the expression was profound. I would like to venture that their illness, - and the loss of independence and the social isolation that this engendered - contributed to a heightened need to communicate inner feelings, and that art became the most powerful way to express these. This was very much a private world that the youth experienced and was typically not shared with many in their social circle. It was often a very private means of self-expression. The emergence of this creative process serves as a channel for their imagination and was very individual and a physical translation of their emotions. In her article, Riley (2001, p54), talks about art being an "expressive language providing an entrée into a relationship with teenagers". I believe art, in all forms, also serves as an insight into their inner feelings.

I am not advocating formal "art therapy" as an approach to helping these youth, as their art took many forms and was very much a private form of expression. In my experience distressed adolescents tend to be unenthusiastic about seeking help from adults, but we could certainly encourage and facilitate them to explore personal art forms as a non-threatening way of expressing their inner feelings and moods including depression. In the examples of the teens' art

forms that I have highlighted, the fear, sadness and inner turmoil are clearly identified.

Rita Charon (2008, p296) describes different genres of narrative such as patient and physician stories, joint medical encounters and medical autobiographies. The creative avenues used by my cohort potentially offers a further form of narrative; one that allows true expression of the person. A deeper interpretation of the artwork, music and poetry shared by my participants shows a multi-dimensional and emotional component that is remarkable. This speaks to an integrative and imaginative depth that holds in tension the spiritual pain and the hope that they feel, and is expressed symbolically through their art.

Finally, the ability to have rational thought and open and honest communication, being empowered with information and having trust in the medical team was a way this group of adolescents was able to express their hope and establish a sense of meaning. Being in control and feeling competent are constructs clearly defined in the resilience literature and were strongly voiced by this cohort. Having trust, being encouraged to be part of active decision making and knowing they were receiving the truth, were all elements that contributed to the teens feeling empowered and provided a way of coping and being able to move forward.

What this truth is and the reality of the hope is important to discuss at this point. Hope remains an emotional attitude that is mirrored in ones values and goals. Patients behave in ways to support their hopes and even if not realizable they may still behave in ways that sustains their hope. This hope can change and fluctuate over time and that for health care providers to care for patients it is not necessary to share the same hopes. Who determines if the hope is false? It is contextual and relative to the judgements made about hope. Having hope, or even false hope, is not usually the issue in health care it is when the realization of this hope is discordant with the medical team or viewed as futile.

These themes are interconnected constructs in the expression of hope for these adolescents. These adolescents voiced a personal narrative, or story, and shared their own unique experience. This is often a lived experience that, if not asked about, is often invisible and closely guarded. These participants express this in reference to their orientation in the world and coloured by their past experiences. Most of my participants describe their new lives in which hope is holistically described and are able to give voice to an inner experience in which meaning plays a key role. With the diagnosis, these adolescents are challenged to reframe their lives and find new meaning in their lives. Their search for meaning is framed positively, references in the future and has a hopeful orientation. This expressed hope may include a hope for a cure, hope for pain relief, and hope to complete a specific task before dying.

This cohort of adolescents demonstrated ways of coping and described ways of finding meaning for him or herself. The factors described above contributed to help protect them in a time of serious adversity. Despite the challenges facing them they demonstrated protective or resilient behaviours that might be

anticipated as part of normal adolescent development. These adolescents consistently demonstrated strategies that promoted their competence and ability to cope.

Reflections on the Conduct of the Study

The American author and broadcaster Tom Bodett quoted that “In school you are taught a lesson and then given a test – In life, you’re given the test that teaches you the lesson”. This was clearly the case for the adolescents in this study. The tough lesson of their diagnosis and subsequent treatment seemed to provide them with lessons in coping, resilience and meaning-finding. And in many ways this sums up my own experience during this research: using a new methodology and my experience has presented tough tests that have taught me a great deal.

The choice of methodology for this study was appropriate as it provided a framework that went beyond the theoretical backbone. As I do not have a social science background, I experienced methodological angst, but given strong theoretical and philosophical foundation of the methodology known as Interpretive Description, and the clinical orientation of the research, the study proceeded. I posed a complicated, contextually laden clinical question and I hoped to generate meaningful knowledge that could influence or inform practice. Interpretive Description “departs from traditional qualitative descriptive approaches in that it assumes nurse investigators are rarely satisfied with description alone and are always exploring meanings and explanations that may yield application implications” (Thorne, 2004, p3)

While the participants’ shared their thoughts and described their feelings as they experienced them, deeper meaning and understanding arose from the interpretation of these descriptions by the researcher. The richness of the data in the early interviews provided the basis for initial interpretation and theories. Later interviews were then used to redefine and confirm the theoretical backbone and concepts that had previously been identified. In this way data collection informed the analysis iteratively, and added dimensions to the construct of hope and spirituality in adolescents that were meaningful and brought new understanding.

The results framed the topic and allowed themes to emerge that identified individual perceptions, and variability or commonalities across the cohort. The objective in Interpretive Description is not to generate entirely original truths, but to provide clinically applicable information that could influence the assessment of patients or planning of programs. Ultimately the purpose of the research is to identify interventions that could inform clinical practice.

Throughout the study I made reflective comments in my field notes. This enabled me to reflect on some of the participants’ demeanour and observations in the interviews, to identify some of the concepts discussed in the paper, and to learn from the collective experience. Before conducting the interviews the planned research had to be approved by the ethics boards at both the University of British Columbia and the University of Bath. During the ethics submission phase a lot of thought and refection took place regarding the

motivation and purpose of the study. Once I was fully committed, I spent time discussing my motivation with my practice-based supervisor and clinical ethicist. This contributed significantly to my understanding as I tried to tease out some of my preconceived ideas, to broaden my vision and to recognize the fact that there was a limit to how much I could direct the study. I believe this period of self-reflection added clarity before and during the study, helped minimized bias, developed me as a researcher and permitted a form of bracketing. Bracketing is a qualitative research method used to mitigate against researcher bias and misconception in the conduct of the study.

Discussions with the ethicist were invaluable as she helped me articulate my motivation for doing this research, choice of topic and my desired outcomes. She enabled me to explore my belief and value systems and challenged me to delve into some of my own existential thoughts. I recognized that I too brought my own personal faith with my own things in which I believe. I was able to articulate and become aware of my own beliefs, and a general sense of being a *spiritual* rather than *religious* person, and very consciously embrace my own specific set of responses to the ultimate existential questions. In the process the ethicist challenged my neutrality and flexibility in my approach to research. In qualitative research it is important to let go of the assumptions one might have developed in constructing the initial analytic framework of the study, and sometimes it takes a neutral person to challenge this. She helped me become aware of my own personal feelings and the preconceived expectations I brought to the research. We take our values with us into the research process and one can argue this presents an obstacle to objectivity, but I believe it brings meaning and depth to the research and enables us to challenge our point of view too.

During the interview phase I tried hard to remain neutral and to acknowledge my biases, and I endeavoured not to allow these to influence the course of the interview. Going into the interviews I assumed the children would be able to articulate their feelings, but I was not certain that they would want to. I had thought I would need to prompt and encourage discussion but the opportunity to share their narrative was so important to the participants that I simply had to allow the full story to unfold, listen, and at times redirect them to focus on our conversation. Even in cases where I had no previous relationship with the child, the opportunity to share their narrative set the tone, and allowed for an even playing field – this was their story of their journey. My task was to let them talk and to listen. It was clear that they wanted to talk and to be heard and this added validity to their participation.

Initially there were more boys than girls who showed interest in the study and enrolled on study. This challenged my preconception that it would be the girls who were more open to sharing and discussing their illness and the topic I was interested in exploring. Similarly, I was anxious that only those with a spiritual orientation or religious bent would consent to the study, but this was ill founded, and I believe a good representation of the target population was obtained. Field notes from my first interview show that I was initially frustrated: I had hoped to get “deeper” but, on reflection, I think this spoke to my bias that all kids would want to talk about their journey, to bare their soul and to share how cancer influenced their “meaning of life”. It was only when I came to review this

particular narrative later that I realized what a rich set of data I had actually obtained, and that the deeper revelations were actually there if I was willing to listen for them. This experience taught me to listen more closely, to trust the process and to allow for the free form of narration that I had selected at the outset.

The dual role of researcher and treating physician was challenged when certain relational issues were shared; I wanted to become the “caregiver” and solve the problem, but this was research and my boundaries had to be firm. This was an important element that I was aware of before I commenced this clinical research but the realities and the significance of the ethical dilemma became heightened as I immersed myself in the research.

In the course of the research I also learned important lessons about myself and this type of research. I learned the value of reflecting honestly on who I am. As physicians we are so often rushed and too busy to take stock of what we do, how we practice or the impact that our work has on others and ourselves. As an oncologist, I am so preoccupied with the work that must be done that even taking time to grieve seems impossible. My own training – and the approach to training the next generation which I still observe today – seems predicated on the assumption that physicians should be detached, and sublimate or sacrifice their own basic human needs for the sake of the profession and their career. I do not want to be this kind of physician or teacher.

In the academic world advancement seems to require one to be not only a good clinician, but also an excellent teacher and a first class researcher. I find myself asking whether I can be all this. I have always enjoyed research and appreciated the value of rigorous methodology. However, while I have enjoyed being part of a research team, I have never had protected time to do my research and so it had become a burden. Forced to find the time to undertake this research study, I not only found myself enjoying the research, but I found I had the time to engage with the participants and really listen to their narratives. I have come to realize that my interest lies in the generation of research ideas, and the discussion and debate around the research question rather than the conduct of the research itself. It is finding the best way to answer a question and identifying the appropriate research methodology that I have found most enjoyable - it is the design and debate that I really enjoy.

I believe I have become more confident as a researcher and am now better able to critically evaluate work and offer methodological suggestions to strengthen research. This study has allowed me the opportunity to consider qualitative methodologies that will best answer the question posed.

Conducting a study engaging adolescents and exploring topics with them about their disease, fears and their hopes was fraught with emotional overtones. This was an intellectual and emotional journey for me. I had initial uncertainty about delving into these young peoples’ beliefs and values but soon came to appreciate their hopes, aspirations, and fears, and to value their honesty and vulnerability. I felt very privileged to have been privy to the thoughts and inner workings of these young people. Sadly, the majority of these children have died since I conducted the interviews in 2012 and 2013, but despite my feelings of

loss and sadness, I am grateful for the gift of the thoughts and insights they shared with me.

This study provided me with the time to ask questions and to immerse myself in these adolescent's narratives. In daily clinical practice, however, we do not often have the privilege of time to discuss and explore these issues with our patients. For me as a researcher, this study was a huge time commitment and brought with it an emotional burden and a sense of my own vulnerability. In the course of caring for these children I believe we, health care workers, encounter and sense the ongoing pain of our patients, and whether we are aware of it or not, this creates stress. To continue to do our job effectively and to cope with this stress I am suggesting we find creative ways to address the hope and the spiritual needs of our patients. I believe that by doing so we will not only help these children, but do a great service to ourselves, and avoid burn-out. To find the sweet spot of caring and of protecting ourselves. In his article, Paul Qualtere-Burcher (2009) describes so nicely the need and quest for patients to seek relationship and, by allowing for "a just distance" in this doctor-patient relationship; one can allow for the right engagement at the right time and still respect selfhood.

Discussing these aspects of humanity make many care providers uncomfortable and worry about adding stress to their job. How to have conversations about hope and spirituality are poorly taught in medical and nursing schools and personal beliefs and values may make these conversations very difficult. I am suggesting these conversations are a very important aspect to care but not everyone has the capacity to embark on these discussions. In a study recently undertaken at the University of British Columbia (Davies, 2016) which including a subset of paediatric oncology families, best practice interactions were explored. Providers who were noted to practice health care in the best possible way were identified by engaging in direct care activities, practicing family-centred care and showing integrity with a commitment to authentic engagement. These practitioners maintained hope for their patients by providing small doses of information consciously and focussing on the family and their needs and gave of their own humanity to patients. Offering care that is holistic brings a sense of fulfilment and interconnectivity to these care providers.

I felt very privileged to have the opportunity to engage with these adolescents in the way that this study permitted. In my field notes after one of the interviews I noted that this experience was a gift. She gave me a gift of time, honesty, and insight into the fragility and vulnerability of all my participants. She later became palliative and the relationship we had been able to establish in the interview allowed for a more profound and meaningful end-of-life journey. It took its toll on me emotionally and highlighted the risks we take in becoming vulnerable as a care provider as we delve into our patients' deeper spiritual struggles. There is a tension that develops between the richness of the relationship and this vulnerability.

About half the adolescents became emotional during the interview and only two actually broke down and cried. However, none of the adolescents, despite being offered to stop the interview, wanted to, or chose to stop the interview.

There was no apology for this display of emotion and there were no consistency in the themes or topics that precipitated the emotion. In an interview with one of my own patients, the participant shared amazingly rich and insightful thoughts and showed great vulnerability. I felt very privileged to have been allowed to share in this way and I was struck by the fact that I would never have known this person in this way if not for the study. Despite the therapeutic relationship we had had, I had never had the time to explore these dimensions. Sadly this young person passed away and the fact that I had been invited into his deepest thoughts made this death even more difficult for me than usual. Perhaps we do not delve too deeply in order to protect ourselves?

It would appear that having taken the lead from the nursing world, reflective practice is becoming more accepted in medical practice and even creeping into medical schools. In his description of professional competence Epstein (2002, p 226) discusses how reflection in daily practice has benefit both for the individual health care professional and the patient. My own experience supports this, and I know I have benefited from taking this time for reflection. It has allowed me a few moments to be human and even, on occasion, to risk being vulnerable.

Limitations of the Study

The methodology used in the study is, I believe, a strength but some may argue a limitation. I tried to stay true to the Interpretive Description methodology and not engage in what Morse (1989) refers to as methodology "slurring". Because Interpretive Description is interpretation beyond the experience of the subject, it is inappropriate to ask the participants to interpret or validate the data themselves. Rather, it is the responsibility of the researcher to identify the common themes within the range of the experiences shared by the participants. In qualitative research it is the interpretation of the researcher that is expressed. The interpretation in this study is my own and was arrived at through immersion in the children's narratives, analysis of the data to extrapolate underlying meanings, identification of common themes and synthesis into the findings described above. I have decided how to interpret the data and in consequence, I take responsibility for my interpretations. Interpretive Description methodology generally accepts small sample sizes and although there were only 13 interviews in my study, the raw data offered a way to explore the phenomenon in a meaningful way and to shed new light on the topic. While the findings may reflect this small number of narratives, they are informed by an analysis of relevant literature, my own clinical experience and the existing body of scientific knowledge.

The use of a second researcher to review the interviews may be seen as blurring, or "slurring" the distinction between different qualitative approaches. However, I believe that having a second researcher provided a form of triangulation and potentially added to the validity and rigour of the study. This probably reflects my insecurity but this allowed a more robust discussion and there was mostly agreement in the identified themes. If the findings are auditable, credible and applicable to the discipline, validity is accepted.

Hope crosses boundaries and may have a nuanced expression in different cultures and religious or spiritual traditions. Although the number of participants is small this cohort was very heterogeneous in terms of culture and gender. Despite these differences similar themes emerged across the cohort and provided a consistent sense of what provides hope for these adolescents.

One of the criteria for participation in the study was that these adolescents were not deemed to be palliative. The interviews were therefore not performed in a palliative setting. Nonetheless, since the commencement of this study more than half the group have died and three are on active palliative care. This reflects the nature of adolescent cancer and the poor prognosis of this group. Both the participants and I knew the graveness of their prognosis, and I believe this knowledge may have heightened the conversation and coloured the adolescent's narratives when discussing meaning of life and hope.

Implications for Practice

The value of qualitative research - especially using Interpretive Description - lies in its clinical applicability. The raw data is interpreted and presented in a way that makes phenomena meaningful and understandable in new ways. Findings from this study need to be presented as truths, not emotionally charged but in a way that the findings will resonate with other clinicians' clinical hunches and, at the same time, offer new insights.
Adolescents enter the circle of our care with a wide variety of beliefs and at different stages of development. The research shows that spirituality is important to many cancer patients, even if it is not prior to their diagnosis. Patients often want their health care providers to ask about it: "They don't want a theological discussion; they just want to know that their providers are interested" (McCormick, 2014). Often this topic is viewed as the Chaplain's job but because of their proximity and relationship with the patient the bedside nurse or the social worker may be best able to create the space for a discussion of spirituality. Embarking on these conversations requires sensitivity and respect and a trusting space for the adolescents but equally not create discomfort for the care provider.

Patients want the health care provider to appreciate the importance of spirituality and hope in the experience they are going through. This exploration with patients is not something that comes easily to everyone and might come with added emotional fatigue and burnout. The personal values and beliefs of the care provider may make having these conversations uncomfortable and so a blanket recommendation to engage in these conversations is cautioned.

Spirituality when it is grounded in a deep sense of oneness with others and when it is expressed in kindness, joy and positivity, it can build resilience and self-efficacy (whether anchored in a religion, an embrace of spirituality, or just an inner core set of beliefs). It does so because such oneness nurtures hope and possibility, empowerment and perhaps an acceptance of living in the present moment. As health care professionals we can bring the importance of balance and integration of hope, the believing in, and reaching for, what might yet be and acceptance in embracing the reality of what is not going to be and of what is. By asking the questions and recognizing the importance of this

dimension of care, patients may be able to make sense of and come to terms with the current circumstance, find an inner peace and purpose, an impetus for reaching beyond their inner fears and pain to see and engage others in the interdependence with them and the universe.

I have seen the grace with which these children bare their illness and I had hoped that this study would add to the body of knowledge in a way that would change clinical practice. Based on this study I can only advocate for and encourage health care workers to ask questions, and to create the space for patients to talk about issues of spirituality and hope. By asking them what is important to them the caregiver may gain insights into the richness and profoundness of their patients.

As clinicians we want to fix what is wrong with our patients, a task our patients want us to fulfil as much as we do. However, in addition to healing the body, there should also be a relationship of openness and trust that allows for emotion to be expressed. What is reasonable for a clinician to do? When is it appropriate to hand over to someone else responsibility for addressing those aspects of healing related to emotion or spiritual pain? The answer is probably unique to each individual patient, but the question poses the clinician with a challenge: how to deal with intimacy yet maintain the therapeutic doctor-patient relationship. A multi-disciplinary approach is clearly needed to approach patients holistically and address all their needs. For the health care team to safely explore spirituality with their patients requires open dialogue, sensitivity and teaching. This approach to medicine does not come naturally to all health care providers but if by recognizing the importance of this dimension in care we can change the culture a little, start having these conversations and as a team holistically support our patients then these adolescents have contributed to our wider understanding and practice.

In his book ‘When Doctors become Patients’, the bioethicist Robert Klitzman (2007, ch12) states “We as doctors need to be aware that: a patient’s experience of illness involves the scientific medical aspects as well as the spiritual and existential aspects. We need to educate doctors to be aware of that. That is not to say that doctors need to pray with patients or to believe anything themselves, but they need to be aware of it to ask patients” … “The more we are aware of what it’s like to be a patient, the better doctors we can be”.

This study highlighted the importance of attending to the rational thinking aspect of care for this cohort. The rational dimension of hope reinforces the need for credible, caring relationships within the illness experience. Practically this speaks to improving authentic caring, improved communication and truth telling. In the adolescent population the role of parental participation needs to be discussed openly. The narratives of this cohort highlighted the importance of parents in creating hope, but also the need for truth telling. Where the presence of parents may make complete truth-telling difficult it is important to create the space for both to occur. Creating the physical and temporal space to talk simply, honestly, and deeply with patients, both alone and with their families, is essential. Together, patients and care providers must make responsible choices about goals, pain and suffering. These engagements must not be just

scientific or disease-related conversations, but must also create the space for conversations about meaning, values, hope and goals. Health care practitioners need to be taught the art of listening and how to engage in conversations where patients and physicians together can develop a responsive and compassionate care plan.

In paediatrics this engagement typically occurs with parents or guardians present, but once the child gains the capacity to be part of the decision-making, the process needs to be discussed and made explicit. This is especially true in the adolescent population where respect for their involvement becomes paramount. Discussions around hope and spirituality are complex and a preferred means of communication needs to be decided by the youth. In these cases the adolescent and their family should be encouraged to create engagement processes that more easily facilitate difficult conversations.

The care plan needs to address not only the science of treatment (including symptom management, clinical trials and all the research facts) but to ask the questions that address the spiritual being. Individuals need to develop their own framework for engagement in which they feel comfortable. Essential discussions should include enquiry into what is meaningful in life, and how prognosis might influence meaning or hope for the patient or family. Patients deserve truthful information about their disease, frank discussion around risk and benefit of treatment and careful wording around hope.

Since school featured as such an important dimension to facilitating hope for these youth, how we integrate school back into their lives needs to be further explored. Hospital - based schooling can address the scholastic demands but not the social and peer dimensions. The participants in this study attribute the latter two reasons as being the important reasons for getting back to school. Patient safety remains paramount and therefore avoidance of a risk of infection avoided but this risk needs to be balanced with the benefit. Perhaps a more lenient approach to returning to school can be adopted with guidance on when not to take unnecessary risk. An example would be when the patient is very myelosuppressed and has low counts, during the viral season and when not feeling well enough in themselves to attend school. I have become less restrictive on returning to school for all my teen patients but especially those with a guarded prognosis.

Having honest conversations with the adolescent patient about the role they want their parents and siblings to play in their disease is very important. This cohort described the importance of parents but perhaps we can facilitate the relationship and continue to foster independence while receiving therapy. Parent support groups, as well as sibling support groups, may allow a collective sharing of wisdom and support. Teen group allows the adolescent to have an evening with hospital peers, a time away from family and a time for fun. Although these did not feature highly in the interviews these groups provide then opportunity to encourage normal milestone development as well as support.

Regarding the role of creative expression in facilitating hope, I do not believe that offering formal art therapy sessions for all our adolescents is a

requirement, or even necessarily a good idea. I do believe that the opportunities for these youth to be able to express themselves in whichever form they choose should be made available. This is especially true for those who spend months in hospital or in isolation for bone marrow transplantation. Merely asking the question and facilitating the desired activity may be enough.

The importance of this study lies in the degree to which it improves our ability to transfer knowledge and enhance practice. The voices of these adolescent patients have shown that being diagnosed with cancer presents both challenges and opportunities, and that in order to not just treat, but also to heal, we need to address the physical, social, psychological and spiritual dimensions of care.

Knowledge Translation

In Naomi Remen's (2001) article on recapturing the soul of medicine, she speaks of the teaching of medicine being more than teaching the science. As she succinctly states "We will need to educate students to find meaning as skilfully as we educate them to pursue medical expertise". I would go one step further and suggest that as we teach the appreciation and importance of the other dimensions of our work, we should bring a more holistic and thoughtful practice to our patients and bring humanity back to the profession.

The educational landscape is changing and health professionals are receiving more instruction on the possible role of religion/spirituality in health care. There are numerous fora available for me to share these research findings. This can be disseminated in formal nursing educational settings, conferences, and in the medical school curriculum. The DPAS (Doctor, Patient and Society) course at the University of British Columbia is a forum to teach the art of medicine, and this can include the role of hope and spirituality in providing care. Being able to provide research findings adds to the science and gives credibility to the recommendations. As Jevne (2007, p 52) says: "A science of hope is necessary to ensure a credible practice of hope, to maximize our ability to use hope ethically & constructively."

The findings of this study have already been shared with a nursing group. I presented the findings and had fruitful dialogue with the American Pediatric Oncology Nurses (APON) education event, in Vancouver on 26th November 2014. This provided an excellent opportunity to share the findings but also to discuss our role in not just the science of what we do but also the art. I lecture to the first year medical students in a block called Medical Ethics in which I give a lecture on truth telling and hope that the findings from this study have allowed me to share some new insights and first hand participant experience. Similarly, in a lecture I give to the final year medical students on Preparing for Medical Practice (PMP) I use adolescent patients to discuss the ethical considerations of treating adolescent patients. These ethical issues include amongst many; confidentiality, truth telling, parental inclusion and how to empower hope.

Teaching and mentoring remain important aspects of my practice. The mentoring in particular allows me to witness growth and empowerment first hand. Seeing registrars or residents finding their passion and their career

paths, and developing into well-rounded paediatricians is very rewarding. Academic medicine is not for everyone, but perhaps in this, more than in other fields of practice, I believe it is essential to keep questioning, to ask “why”, and to maintain a thirst for knowledge. “Certainly the primary imperative of a physician is to be skilled in medical science, but if he or she does not probe a patient’s soul, then the doctor’s care is given without caring, and part of the sacred mission of healing is missing.” (Groopman, 2004, p *xiv*)

Suggestions for further research

The findings from this study have encouraged me to further explore resilience in the cancer patient and more specifically the dimensions of hope and spirituality. The potential cohorts could be in the palliative setting, immigrant adolescent patients and the parents of these patients. Further exploration of the ethnic and cultural influences on these constructs will widen our appreciation and could further guide our practice.

I would like to further explore the existential philosophy that was highlighted in this study, acknowledging the importance of the relationship and mutual humanity shared with the participant and by extrapolation to the patient. The manner in which these existential factors might influence health outcomes needs further exploration. Thoughtful study design and strategic methodologies will need to be employed to provide much-needed answers to the questions in this realm, especially in the paediatric population. Already much work has been done on the doctor - patient relationship but this can be taken to a new level and could explore more deeply our shared humanity, which in turn could potentially improve health care effectiveness, quality of life and general well-being.

This study will not change the survival or the cure rates of our children and having hope is not enough to beat the odds, but by empowering hope and appreciating spirituality we may provide adolescents with the strength and the courage to carry on, to endure chemotherapy and bone marrow transplantation and to retain their evolving humanity. I can find no better summary of the value of this research than the words of one of my participants: *“Gathering up the reasons to hope. That is the real fight against cancer” Steve.*

References

Alfred, R. (2003). The First International Conference on Organisational Spirituality (ICOS) University of Surrey, Guildford. ISBN 1-84469-0040.

Benard, B. (1991). The foundation of the resiliency framework. *Resiliency in Action Website.* Retrieved February 14, 2017, from https://www.resiliency.com/free-articles-resources/the-foundations-of-the-resiliency-framework/.

Blakemore, S.-J. and Frith, U. (2005). *The learning brain: Lessons for education*. Oxford, UK: Blackwell Publishing. ISBN: 1405106220, 9781405106221.

Bleyer, W.A. (1997). The U.S pediatric cancer trial programmes: International implications and the way forward. *European Journal of Cancer*, 33, 1439-1447.

Bleyer, W.A., Tejeda, H., Murphy, S.B., Robinson, L.L., Ross, J.A., Pollock, P.H. (1997). National cancer clinical trials: children have equal access, adolescents do not. *Journal of Adolescent Health,* 21, 366-373.

Blos, P. (1979). *The Adolescent Passage.* Madison, CT: International Universities Press. ISBN: 0823600953.

Blustein, D.L. (1991). Self-identity in late adolescents. *Journal of Adolescent Research,* 6(4), 437-453.

Beauchamp, T. and Childress, J. (2009). *Principles of biomedical ethics* (5th ed.). Oxford, UK: Oxford University Press. ISBN: 0-19-514331-0.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology Health Illness,* 4(2), 167-82

Cantrell, M. (2004). A predictive model of hopefulness for adolescents. *Journal* of Adolescent Health, 35(6), 478-485.

Caputo, J.D. (1987). *Radical Hermeneutics: Repetition, Deconstruction and the Hermeneutic Project.* Bloomington and Indianapolis: Indiana University Press. ISBN: 978-0-415-64458-7.

Carver, CS. and Scheier, M. (1982). Control theory: A useful conceptual framework for personality–social, clinical, and health psychology. *Psychological Bulletin*, 92(1), 111-135.

Charon, R. (2001). Narrative medicine: A model for empathy, reflection, profession and trust. *Journal of the American Medical Association,* 286(16), 1897-1902.

Charon, R. (2001). Narrative medicine: Form, function and ethics. *Annuals of Internal Medicine*, 134(1), 83-87.

Charon, R. and Wyer, P. (2008). Narrative evidence based medicine. *Lancet*, 371(9609), 296-7.

Charon, R. (2017). *The principles and practice of narrative medicine.* Oxford, UK: Oxford University Press. ISBN: 9780199360192.

Chochinov, H.M. and Cann,B.J. (2005). Interventions to enhance the spiritual aspects of dying. *Journal of Palliative Medicine,* 8(1), S103-115.

Cicchetti, D. and Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Annals of the New York Academy of Science*, 1094, 1-12.

Coleman, J. and Hagell, A. (Ed.). (2007). *Adolescence, risk and resilience. Against the odds*. Hoboken, NJ: John Wiley and Sons, Inc. ISBN: 978-0-470-02503-1.

Cook, C.C. (2006). Addiction and spirituality. *Addiction*, 101(5), 761.

Cotton, S. (2006). Spirituality and religion in patients with HIV/AIDS. *Journal of General Internal Medicine,* 21(5), 5-13.

Crist, J.D. and Tanner, C.A. (2003). Interpretation/analysis methods in hermeneutic interpretive phenomenology. *Nursing Research*, 52(3), 202-205.

Davies, B. and Strahlendorf, C. (2016). Best Practice in Provider/Parent Interaction. *Qualitative Health Research*, 27(3) 403-420

deWitt, L. and Ploeg, J. (2006). Methodological issues in Nursing Research. Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advance Nursing*, 55(2), 215-229.

Dreyfus, H. and Rabinow, P. (1983). The subject and power*.* In: Michel Foucault*: Beyond structuralism and hermeneutics.* Chicago, IL: University of Chicago Press. ISBN: 13-978-0226163123.

Dutcher, J. (1999). Seeking meaning and hope. *Psycho-Oncology*, 8(5), 378-385.

Epstein,R.M. (2002). Defining and Assessing Professional Competence. *Journal of the American Medical Association*, 287(2), 226-235.

Fowler, J.W. (1981). *The stages of faith: The handbook of spiritual development in childhood and adolescence.* Thousand Oaks, CA: Sage Publishing. ISBN: 0-06-062866-9.

Fowler, J.W. (1995). *Stages of Faith: The Psychology of Human Development*. Harper Collins. ISBN: 0-06-062866-9.

Fowler, J.W. (2004). Stages of faith and identity: Birth to teens. *Child and Adolescent Psychiatry Clinics of North America,* 13, 17-33.

Fochtman, D. (2008). Phenomenology in pediatric cancer nursing research. *Journal of Pediatric Oncology Nursing*, 25(4), 185-192.

Frankl, V. (1946). *Man's Search for Meaning*. Vienna, AT: Beacon Press. ISBN: 080701429X.

Furman, L.D., Benson, P.W., Grimwood, C., Canda, E. (2004). Religion and spirituality in social work education and direct practice at the millennium: A survey of UK social workers. *British Journal of Social Work*, 34(6), 767-792.

Ginsburg, K. (2015). *Building resilience in children and teens: Giving kids roots and wings* (3rd ed.). Grove Village, IL: American Academy of Pediatrics. ISBN: 978-1-58110-866-8.

Glicken, M.D. (2007). *Social work in the 21st Century*. *An introduction to social welfare, social issues, and the profession.* Thousand Oaks, CA: Sage Publishing. ISBN: 978-1-4129-7578-0.

Goffman, E. (1986). Stigma: notes on the management of spoiled identity. First Touchstone Edition. ISBN: 0-671-62244-7

Groopman, J. (2005). *The anatomy of hope: How people prevail in the face of illness*. New York, NY: Random House, Inc. ISBN: 0-375-75775-9.

Gum, A. and Snyder, C.R. (2002). Coping with terminal illness: The role of hopeful thinking. *Journal of Palliative Care,* 5(6), 883-894.

Haase, J. (1992). Simultaneous concept analysis of spiritual perspective, hope, acceptance and self-transcendence image. *Journal of Nursing School*, 24(4), 141-147.

Haase, J. (1994). Experiences of completing cancer therapy: Children's perspectives. *Oncology Nursing Forum*, 21(9), 1483-1492.

Haase, J.E., Heiney, S.P., Ruccione, K.S., Stutzer, C. (1999). Research triangulation to derive meaning-based quality-of-life theory: Adolescent resilience model and instrument development. *International Journal of Cancer Supplemental*, 12, 125-131.

Haase, J. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*, 21(3), 145-149.

Haase, J. (2007). Psychometric properties of the Herth-Hope Index in adolescents and young adults with cancer. *Journal of Nursing Measurement*, 15(1), 3-23.

Hardwig, J. (2005). Families and futility: Forestalling demands for futile treatment. *Journal of Clinical Ethics*, 16(4), 335-344.

Hendricks-Ferguson, V. (2008). Hope and spiritual well-being in adolescents with cancer. *Western Journal of Nursing Research,* 30(3), 385-401.

Hart, T. (2003). *The secret spiritual world of children*. Makawao, HI: Inner Ocean Publishing. ISBN: 1-930722-19-2.

Herth, K. (1991). Development and refinement of an instrument to measure hope. *School of Inquiry of Nursing Practice*, 5(1), 39-51.

Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing,* 17(10), 1251-1259.

Hinds, P. (1984). Inducing a definition of 'hope' through the use of grounded theory methodology. *Journal of Advanced Nursing*, 9(4), 357-362.

Hinds, P. (1988), Hopefulness and self-sustaining process in adolescents with cancer. *Nursing Research*, 37(6), 336-340.

Hinds, P. (1988). Adolescents hopefulness in illness and health. *Advanced Nursing Science,* 10(3), pp.79-88.

Hinds, P. (2000). Fostering coping by adolescents with newly diagnosed cancer. *Seminars in Oncology Nursing*, 16(4), 317-327.

Hinds, P. (2004). The hopes and wishes of adolescents with cancer and the nursing care that helps. *Oncology Nursing Forum*, 31(5), 927-934.

Hope Studies Central http://www.hope-lit.ualberta.ca

Horgan, M. 2009, 'Stepping Stones Program', *National Hospice and Palliative Care Organization*, ChiPPS

Mowat, H. and O'Neill, M. (2013). Spirituality and aging: Implications for the care and support of older people. Institute for Research and Innovation in Social Services. Insights (Evidence summaries to support social services in Scotland). Retrieved on February 14, 2017 from https://www.iriss.org.uk/sites/default/files/iriss-insight-19.pdf.

Juvakka, J. and Kylma, J. (2009). Hope in adolescents with cancer. *European Journal of Oncology Nursing*, 13(3), 193-199.

Jevne, R. (1993). Enhancing hope in the chronically ill. *Humane Medicine*, 9(2), 121-130.

Jevne R. (2007). An introduction to the intentional use of hope*. Journal of Allied Health*, 36(1), 52-56.

Josselson, R. (1980). Ego development in adolescence. *Handbook of Adolescent Psychology.* Hoboken, NJ: Wiley &Sons. ISBN: 978-470-14921-8.

Kane, J. (2001). Alleviating the suffering of seriously ill children. *Journal of Hospice and Palliative Medicine*, 17(3), 165-172.

Kaufmann, W. (1975). *Existentialism from Dostoevsky to Satre*. Penguin Group. ISBN: 0452009308

Kaufmann, W. (2013). *Neitzsche: Philosopher, Psychologist, Antichrist*. Princeton University Press. ISBN: 9780691 160269

Kautz, D. (2008). Inspiring hope in our rehabilitation patients. *Rehabilitation Nursing*, 33(4), 148-153.

Klitzman, R. (2007). *When doctors become patients*. Oxford, UK: Oxford University Press. IBSN 978-0-19-532767-0.

Kodish, E. and Post, S.G. (1995). Oncology and hope. *Journal of Clinical Oncology*, 13, 1817-1822.

Kodish, E. (2014). Patient involvement in informed consent for pediatric phase I cancer research. *Journal of Pediatric Hematology Oncology*, 36(8), 635-40

Konopka, G. (1973). Formation of values in the developing person. *American Journal of Orthopsychiatry*, 43(1), 86-96.

Kumpfer, K.L. and Summerhays, J.F. (2006). Preventative approaches to enforce resilience among high-risk youth. *Annals of the New York Academy of Science*, 1094, 151-163.

Kuttner, L. (2006). *A Child in pain*. Vancouver, BC: Hartley and Marks Publishers. ISBN: 0881791288.

Lau, P. (2006). Spirituality as a positive youth development construct. *International Journal of Adolescent Mental Health*, 18(3), 363-370.

Linaby, A. and Ross, J.A. (2008). Childhood and adolescent cancer survival in the U.S. by race and ethnicity. *Cancer*, 113(9), 2575-2596.

Lindseth, A. and Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Science*, 18(2), 145-153.

Lopez, K. and Willis, D. (2004). Descriptive versus interpretive phenomenology: Their contribution to nursing knowledge. *Qualitative Health Research*, 14, 726-735.

Luthar, S.S. and Zigler, E. (1991). Vulnerability and competence: A review of research on resilience in childhood. *American Journal of Orthopsychiatry*, 61(1), 6-22.

Luthar, S. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71(3), 543-562.

Martocchio ,B. (1982). *Living while dying*. Upper Saddle River, NJ: Prentice-Hall Publishing. ISBN 0-87619-922-8.

Masten, A. (2006). Competence and resilience in development. *Annuals of the New York Academy of Science*, 1094, 13-27.

Maxwell, J.A.. (2005). *Qualitative research design*. Thousand Oaks, CA: Sage Publishing. ISBN 0-7619-2608-9.

Matthews, E.E and Cook, P.F. (2009). Relationships among optimism, well-being, self transcendence, coping and social support in women with breast cancer. *Psycho-Oncology*, 18(7), 716-726.

McSherry, W. and Cash, K. (2004). The language of spirituality: An emerging taxonomy. *International Journal of Nursing Studies,* 41(2), 151-161.

McSherry, W. (2006). *Making sense of spirituality in nursing and health care practice: An interactive approach* (2nd ed.). London, UK: Jessica Kingsley Publishers. ISBN 978-1-84310-65-3.

McSherry,W.and Smith, J. (2007). How do children express their spiritual needs. *Paediatric Nursing*, 19(3), 17-20.

McSherry, W., McSherry, R., Watson, R. (Ed.). (2012). *Care in nursing principles, values and skills.* Oxford, UK: Oxford University Press. ISBN 9780199583850.

Moadel, A. (1999). Seeking meaning and Hope. Self-reported spiritual and existential needs among an ethnically diverse cancer patient population. *Psycho-Oncology*, 8, 378-385.

Mencken, H. (2008). *Selected Writings of Friedrich Nietzsche*, Floyd, VA: Wilder Publishers. ISBN 978-1604593334

Menninger, K. (1959). The academic lecture: Hope. *American Journal of Psychiatry,* 116, 481-491.

Mohrmann, M.E. (2007). *Attending children. A doctor's education*. Washington, DC: Georgetown University Press. ISBN 1-58901-034-X.

Muellen, C.R. (2010). Spirituality in children. *Pediatric Nursing*, 36(4), 197-208.

Nekolaichuk, C.L., Jevne, R.F., Maguire, T.O. (1996). The delineation of a hope structure based on personal meaning. *International Journal of Psychology*, 31(3-4), 424-463.

Nekolaichuk, C.L., Jevne, R.F., Maguire, T.O. (1999). Structuring the meaning of hope in health and illness. *Social Science and Medicine*, 48(5), 591-605.

Nelson, R. (2014). Spiritual needs of cancer patients important part of care. Retrieved from *Medscape Medical News>Oncology* article published on August 22, 2014, www.medscape.com/viewarticle/830317.

Neuman, M.E. (2011). Addressing children's beliefs through Fowler's stages of faith. *Journal of Pediatric Nursing*, 26, 44-50.

Nowotny, M.L. (1989). Assessment of hope in patients with cancer: Development of an instrument. *Oncology Nursing Forum*, 16(1), 57-61.

Oldnall, A. (1996). A critical analysis of nursing: Meeting the spiritual needs of patients. *Journal of Advanced Nursing,* 23, 138-144.

Oser, F.K. (1991). The development of religious judgment. *New Directions for Child Development,* 1991(52), 5-25.

Oxford English Dictionary. (1996). Oxford, UK: Oxford University Press, ISBN 0-19-860046-1.

Penson, R.T. (2007). Hope. *Oncologist,* 12(9), 1105-1113.

Phillips, C., Haase, J., Monahan, P. (2005). Measurement of hope in adolescents and young adults with cancer (AYA). *Oncology Nursing Forum*, 32(1), 169-170.

Piaget, J. (1977). The role of action in the development of thinking. *In Knowledge and Development*, pp. 17–42.

Piaget, J. (2006). *The Moral Judgement of the Child*. The Free Press. ISBN: 0684833301

Polkinghorne, D.E. (2005). Language and meaning, data collection in qualitative research. *Journal of Consulting Psychology*, 52(2), 137-145.

Poveda, T.G. (1972). A perspective on adolescent social relations. Psychiatry, 35(1), 32-47.

Prasannar,R.D., Suruluvel R., Kakshmi S., Abdul Nazir, C.P. (2011). Patient reported outcomes: A new era in clinical research. *Perspectives in Clinical Research*, 2(4), 137-144.

Qualtere-Burcher,P. (2009). The just distance: Narrativity, singularity, and relationality as the source of new biomedical principle. *Journal of Clinical Ethics*, 20(4), 299-309.

Rabinow, P. (2010). *The Foucault Reader*. New York, NY: Vintage Books. ISBN 0-394-52904-9.

Remen, R.N. (2001). Recapturing the soul of medicine. *Western Journal of Medicine,* 174(1), 4-5.

Resnick, M.D. (2000). Resilience and protective factors in the lives of adolescents. *Journal of Adolescent Health*, 27(1), 1-12.

Riley, S. (2001). Art therapy with adolescents. *Western Journal of Medicine*, 175(1), 54-57.

Roehlkepartain, E.C. (2006). *The Handbook of Spiritual Development in Childhood and Adolescence.* Thousand Oaks, CA: Sage Publishing. ISBN 0-7619-3078-7.

Rorty, R. (1981). *Philosophy and the Mirror of Nature.* Princeton, NJ: Princeton University Press. ISBN 0-691-020`6-7.

Ruddick, W. (1999). Hope and deception. *Bioethics*, 13(3), 343-357.

Russinova, Z. (1999). Providers' hope-inspiring competence as a factor optimizing psychiatric rehabilitation outcomes. *Journal of Rehabilitation*, 65(4), 50-57.

Rustoen, T. (1995). Hope and quality of life. *Cancer Nursing*, 18(5), 355-361.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health,* 33, 77-84.

Schnell, T. (2010). Existential indifference: Another quality of meaning of life. *Journal of Humanistic Psychology*, 50(3), 351-373.

Selman, R. (1980). *The growth of interpersonal understanding: Developmental and clinical analyses (Developmental psychology series)*. Cambridge, MA: Academic Press. ISBN 0126364508.

Siegler, R.S., Eisenberg, N., DeLoache, J.S., Saffran, J. (2006). *How children develop* (2nd ed.). Gordonsville, VA: Worth Publishers.

Simon C., Zyzanski SJ., Eder M., Raiz P., Kodish ED., Siminoff LA. (2003). Groups potentially at risk for making poorly informed decisions about entry into clinical trials for childhood cancer. *Journal of Clinical Oncology,* 21(11), 2173-2178.

Singleton, L. (2007). Developmental differences and their clinical impact in adolescents. *British Journal of Nursing,* 16(3), 140-143.

Smith, J. and McSherry, W. (2004). Spirituality and Child Development: A concept analysis. *Journal of Advanced Nursing*, 45(3), 307-315.

Solomon, R.C. (Ed.). (2004). *Existentialism* (2nd ed.) Oxford, UK: Oxford University Press. ISBN 0-19-517463-1

Tanyi, R.A. (2007). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing,* 39(5), 500-509.

Taylor, C. (1989). *The source of the self*. Cambridge, MA: Harvard University Press. ISBN 0-674-82426-1.

Taylor, C. (2007). *A secular age*. Cambridge, MA: Harvard University Press. ISBN: 978-0-67402-676-6.

Taylor, E.J. and Amenta, M. (1995). Spiritual care practices of oncology nurses. Oncology *Nursing Forum,* 22, 31-39.

Thorne, S. (1997). Focus on qualitative methods. *Research Nursing and Health,* 20, 169-177.

Thorne, S., Reimer Kirkham, S., O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1-21.

Thorne, S. (2008). *Interpretive Description*. Walnut Creek, CA: Left Coast Press. ISBN: 978-1-59874-330-2.

Wagnild, G.M. and Young, H.M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, 1(2), 165-178.

Wall, C., Glenn, S., Mitchinson, S., Poole, H. (2004). Using a reflective diary to develop bracketing skills during phenomenological investigation. *Nursing Research*, 11(4), 20-29.

Wong-Wylie, G. and Jevne, R. (1996). The influence on hope of physician/patient interactions with persons living with HIV. *International Journal of Psychology*, 31(3-4), 424-462.

Wong-Wylie, G. and Jevne, R.F. (1997). Patient hope: Exploring the interactions between physicians and HIV seropositive individuals. *Qualitative Health Research*, 7(1), 32-56.

Woodgate, R. (2000). Part II: A critical review of qualitative research related to children's experiences with cancer. *Journal of Pediatric Oncology Nursing*, 17(4), 207-228.

Woodgate, R. (2003). The 2002 Schering Lecture "Children's cancer symptom experiences: Keeping the spirit alive". *Cancer Oncology Nursing Journal*, 13(3), 142-150.

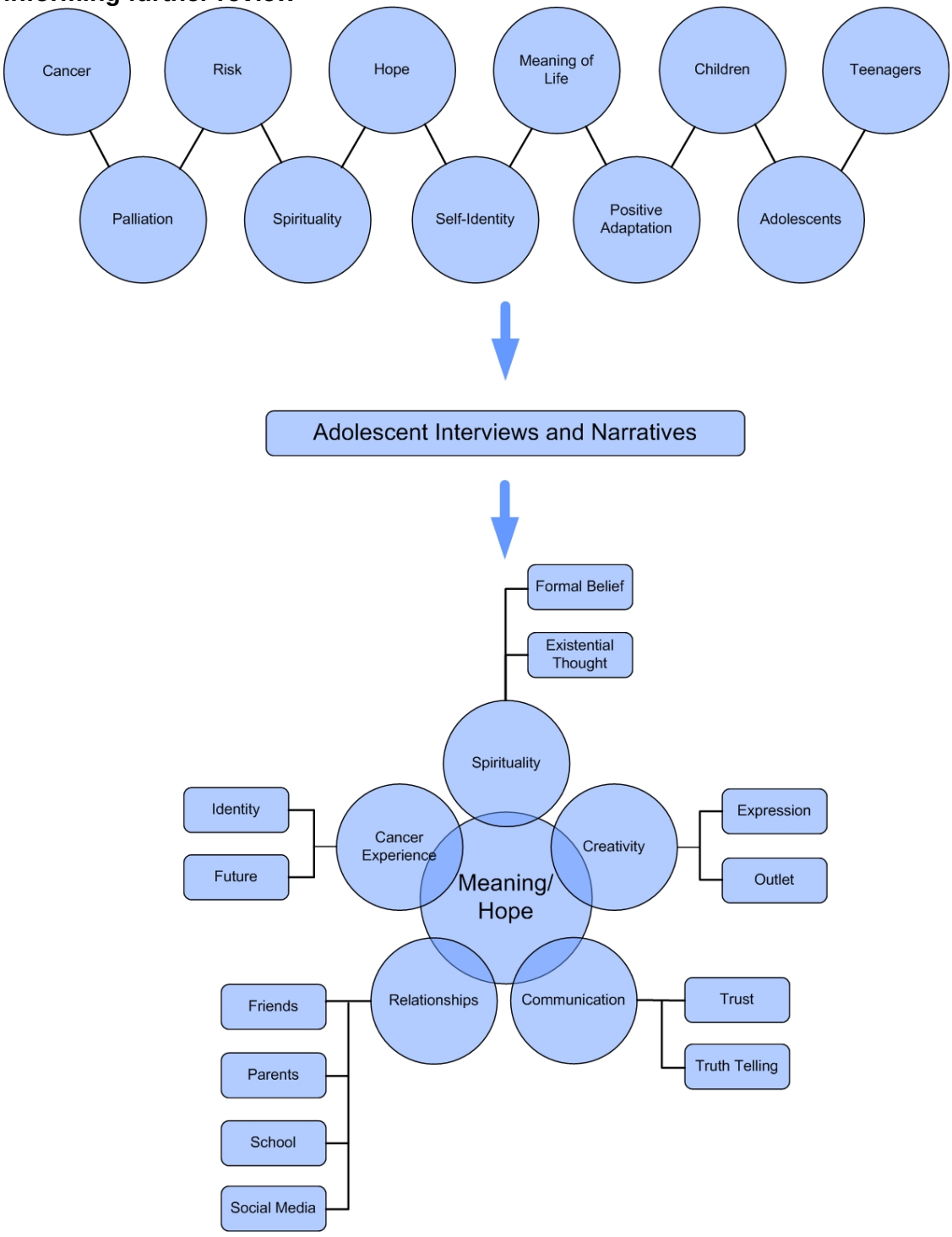
Woodgate, R. (2005). A different way of being: Adolescent's experiences with cancer. *Cancer Nursing,* 28(1), 8-15.

Woodgate, R. (2006). The importance of being there: Perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 23(3), 122-134.

Zimmerman, M.A. (2005). Adolescent resilience: A framework for understanding healthy development in the face of risk. *Annual Review Public Health*, 26, 399-419.

Appendices

Appendix 1: Schematic representation of literature review and interviews informing further review



Appendix 2: Advertisement

Hope and the meaning of life in the face of cancer

What lies within?...

If you are between 15 and 19 years of age you may be eligible to participate in a study exploring how you cope with the diagnosis of cancer. How you find optimism and how your diagnosis influences your meaning of life.

How can I help?

If you are interested in participating and require further information please contact the research nurse Cecilia Lau or your primary nurse for more information. All information you provide will be kept confidential. The study will involve a one-on-one interview. The total amount of time it will take to participate in this study will not exceed 90 minutes.

You will receive an honorarium for participating in this study.

How do I get involved?

Call the Research Coordinator, Cecilia Lau, at 604-875-2345 ext 7614 or send an email to clau4@cw.bc.ca

Appendix 3: Consent

Consent to take part in a Research Study conducted by the Division of Hematology/Oncology/Bone Marrow Transplantation of the UBC Department of Paediatrics

Hope and the meaning of life in adolescent cancer patients – a phenomenological study.

Principal Investigator: Dr. Caron Strahlendorf (604) 875-3576
Co-Investigator: Dr. Phillip Crowell

If you are a parent or legal guardian of a child who may take part in this study, permission from you and the assent (agreement) of your child may be required. When we say "you" in this consent form, we mean you or your child; "we" means the doctors and other staff.

INTRODUCTION

You _____are being invited to take part in this study because you are an adolescent subject diagnosed with a malignancy. You are presently undergoing treatment for this malignancy and we are interested in understanding how you are coping with your diagnosis and how this diagnosis has impacted your life.

YOUR PARTICIPATION IS VOLUNTARY

Your participation is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate, you will be invited to sign this form. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reasons for your decision.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate nor will you lose the benefit of any medical care to which you are entitled or are presently receiving.

Please take time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide.

WHO IS CONDUCTING THE STUDY?

This study is being carried out by Dr Caron Strahlendorf one of the oncologists in the division of pediatric oncology.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to explore how adolescents cope with the diagnosis of cancer, what being a cancer patient means to them and what impact this diagnosis may have on the meaning of life.

WHO CAN PARTICIPATE IN THE STUDY?

Adolescent subjects diagnosed with a malignancy presently being treated with chemotherapy or bone marrow transplantation.
You are between the ages of 15 and 19 years old.
English speaking and have clear thought processes.

WHO SHOULD NOT PARTICIPATE IN THE STUDY?

If you do not wish to participate in the study and do not give your consent to participate.
If you have developmental delay or have recently had extensive brain surgery.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 12 to 16 adolescent subjects will participate.

WHAT WILL HAPPEN ON THIS STUDY?

Once you consent to participate in this study, you will be contacted by Dr. Strahlendorf and an interview will be scheduled. This will take place at your convenience and take place in a private setting that you feel comfortable to talk in. The interview may take about 60- 90 minutes but you may stop at any time. Your thoughts and ideas on the topic of coping, important aspects of your life and the impact of the diagnosis on your life will be discussed. Your conversation will be digitally recorded but no names or numbers identifying you will appear on the recording or on any notes taken during the conversation or after. The recordings will be transcribed confidentially and then stored in a locked drawer till all the analysis has been completed. Once this is done the recordings will be erased. After a few teenagers, similar to you, have participated in the study and common themes (or information or ideas) are identified, we may want to discuss these with you at a later date. Again this will be in private and all information shared will be kept confidential and reported in an anonymous way. All recordings will be transcribed (written in words) after the interviews and all transcriptions will be without any personal identifying information. The digital recording will be deleted. The transcriptions and analysis of data will be retained for 5 years.

HOW LONG WILL THE STUDY LAST?

The study should take about two years to complete. You may ask to be given a summary of the study results after they are written up.

WHAT ARE THE RISKS OF THE STUDY?

Discussion of your disease and the impact on your life may be distressing and cause anxiety. If this should occur the interview will stopped and a social worker or psychologist will be available if required. Though unlikely, there is a potential risk of the loss of your confidentiality.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

There is no direct benefit to participating in this study but we hope that the information learned from this study will provide an insight into your experience and benefit other subjects in the future.

WHAT ARE THE ALTERNATIVES TO THE STUDY?
Participation is entirely voluntary.

WHAT HAPPENS IF YOU DECIDE TO WITHDRAW CONSENT TO PARTICIPATE?
You may withdraw from this study at any time without providing any reasons. If you decide to enter the study and to withdraw at any time in the future, there will be no penalty or loss of benefits to which you are otherwise entitled, and your future medical care will not be affected. If you do decide to withdraw from this study, you should contact the Principal Investigator at 604-875-3576 or your primary nurse.

The study doctor may decide to discontinue the study at any time, or stop the interview at any time, if she feels that it is in your best interests.

If you choose to enter the study and then decide to withdraw at a later time, all data collected about you during your enrolment will be destroyed.

WHAT WILL THE STUDY COST?
You will not incur any personal expenses as a result of participating in this study. You will receive a gift voucher of $20.00 for taking part in this study.

WILL TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?
The confidentiality of you and your child will be respected. No information that discloses your or your child's identity will be released or published without your specific consent to the disclosure. Only a study number assigned to you will be used on all research related data. However, research records identifying you/your child may be inspected at the office of the investigator in the presence of the Investigator or his or her designate by representatives of the University of British Columbia (UBC) Research Ethics Boards for the purpose of monitoring the research. However, no records which identify you by name will be allowed to leave the Investigators' offices.

WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING PARTICIPATION?
Should you have any questions or desire further information with respect to this study, you should contact the Principal Investigator at 604-875-3576.

WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT THE RIGHTS OF A SUBJECT DURING THE STUDY?
Signing this consent form in no way limits your legal rights against the investigator or anyone else.

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, contact the Research Subject Information Line in the University Of British Columbia Office Of Research Services by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free number 1-877-822-8598).

WILL I RECEIVE A COPY OF THE CONSENT FORM?
You have received a copy of this consent form and you will be provided with a signed and dated copy for your records should you agree to participate in this study.

SUMMARY AND SIGNATURES

I have been fully informed as to the procedures to be followed, including a description of the risks, and benefits. In signing this consent form, I agree to participate in this study and I understand that I am free to withdraw my consent at any time, without giving a reason, and without consequence to continuing care of myself.

My signature indicates that I have read and understood the above information, that I have discussed this study with the physician and her staff, and that I have decided to participate, based on the information provided. The parent(s)/guardian(s) and the investigator are satisfied that the information contained in this consent form has been fully explained and discussed with the child and that he/she is able to fully understand it, that all questions have been answered, and that the child assents to participating in the research.

Check List

- I have read and understood the subject information and consent form.
- I have had sufficient time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time without changing in any way the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I have read this form and I freely consent to participate in this study.
- I have been told that I will receive a dated and signed copy of this form.

_____	_____	
Name of Subject (PRINT)	Signature	DATE
_____	_____	
Name of Parents/Guardians (PRINT)	Signatures	DATE
_____	_____	
Principal Investigator or (PRINT)	Signature	DATE

copy: Parent/Guardian, Investigator's File

SUBJECT'S ASSENT TO PARTICIPATE IN RESEARCH

I have had the opportunity to read this consent form, to ask questions about my participation in this research, and to discuss my participation with my parents/guardians. All my questions have been answered. I understand that I may withdraw from this research at any time, and that this will not interfere with the availability to me of other health care. I will receive a signed and dated copy of this

consent form. I agree for now to participate in this study.

_____ Name of Subject

_____ Signature

_____ Date

Appendix 4: REB Approval

CHILDREN'S & WOMEN'S HEALTH CENTRE OF BRITISH COLUMBIA
AN AGENCY OF THE PROVINCIAL HEALTH SERVICES AUTHORITY

UBC C&W Research Ethics Board
A2-136, 950 West 28th Avenue
Vancouver, BC V5Z 4H4
Tel: (604) 875-3103 Fax: (604) 875-2496
Email: cwreb@cw.bc.ca
Website: http://www.cfri.ca/reb

ETHICS CERTIFICATE OF MINIMAL RISK APPROVAL

PRINCIPAL INVESTIGATOR:	INSTITUTION / DEPARTMENT:	UBC C&W NUMBER:
Caron Strahlendorf	UBC/Medicine, Faculty of/Paediatrics	H09-01584

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

Institution	Site
Children's and Women's Health Centre of BC (incl. Sunny Hill)	Child & Family Research Institute

Other locations where the research will be conducted:
N/A

CO-INVESTIGATOR(S):
N/A

SPONSORING AGENCIES:
N/A

PROJECT TITLE:
Hope and the meaning of life in adolescent cancer patients – a phenomenological study.

REMINDER: The current UBC Children's and Women's approval for this study expires: June 20, 2012

The UBC Children's and Women's Research Ethics Board Minimal Risk Committee has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants ethics approval. Note that institutional approval is required before research can commence at C&W.

This approval applies to research ethics issues only. The approval does not obligate an institution or any of its departments to proceed with activation of the study. The Principal Investigator for the study is responsible for identifying and ensuring that resource impacts from this study on any institution are properly negotiated, and that other institutional policies are followed. The REB assumes that investigators and the coordinating office of all trials continuously review new information for findings that indicate a change should be made to the protocol, consent documents or conduct of the trial and that such changes will be brought to the attention of the REB in a timely manner.

DOCUMENTS INCLUDED IN THIS APPROVAL:			APPROVAL DATE:
Document Name	**Version**	**Date**	
Protocol:			
Hope and Meaning of Life in Adolescent Cancer Patients	1	May 8, 2011	
Research protocol	2	June 7, 2011	
Consent Forms:			
Consent	1	May 8, 2011	
Consent	2	June 7, 2011	**June 20, 2011**
Advertisements:			
Advertisement	1	May 8, 2011	
Other Documents:			
Bath ethics application	1	May 8, 2011	
Proviso response	N/A	June 7, 2011	
Interview guide	1	June 7, 2011	

CERTIFICATION:
In respect of clinical trials:
1. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the Food and Drug Regulations.
2. The Research Ethics Board carries out its functions in a manner consistent with Good Clinical Practices.

3. This Research Ethics Board has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site. This approval and the views of this Research Ethics Board have been documented in writing.
The documentation included for the above-named project has been reviewed by the UBC Children's and Women's Research Ethics Board, and the research study, as presented in the documentation, was found to be acceptable on ethical grounds for research involving human subjects and was approved by the UBC Children's and Women's Research Ethics Board.
Approved by one of: **Dr. Marc Levine, Chair**

Appendix 5: Example of a transcript with field notes and coding.

November 13, 2012
5BMS (In clinic – duration 39 minutes)

1.	INTERVIEWER: THIS IS COMPLETELY CONFIDENTIAL.
2.	SO WHATEVER YOU AND I DISCUSS TODAY IS BETWEEN YOU AND I
3.	I DO TAPE IT BUT THAT'S BECAUSE I THEN…
4.	Participant: Review it?
5.	
6.	TYPE IT OUT
7.	Oh
8.	
9.	AND THEN THIS TAPE GETS DISCARDED AND I DON'T USE YOUR NAME OR PERSONAL IDENTIFIERS IN IT
10.	OKAY? I WILL JUST SAY AB OR WHATEVER INITIALS I ASSIGN TO YOU OR YOU'RE GIVEN A NUMBER.
11.	UMM...AND WE CAN STOP AT ANYTIME, JUST LET ME KNOW.
12.	WE'LL JUST SEE HOW IT GOES.
13.	Ok
14.	
15.	DO YOU KNOW WHAT THIS INTERVIEW IS ABOUT?
16.	Ah I can't really 34remember something about what it is that gives me hope, right?
17.	
18.	THAT'S CORRECT, AND HOW YOU FIND YOUR MEANING
19.	I'M TRYING TO UNDERSTAND HOW CANCER IMPACTS YOUR VIEW ON LIFE.
20.	STILL HAPPY TO PARTICIPATE? ARE YOU READY TO BEGIN?
21.	SO WHAT IS IT THAT BRINGS YOU MEANING?
22.	For me personally, umm...I think it is because I took two psychology courses
23.	and I know that a lot of things and I have realized a lot of things that we do in life
24.	is completely mind over matter so I'm always thinking mind over matter
25.	and it's like you know in my mind I can heal myself, so in my mind I'm healing myself
26.	and that kind of gives me that hope.
27.	
28.	HOW DO YOU ACTUALLY DO THAT?
29.	It's a lot of just, it's like counseling but I counsel myself in my head.
30.	I think of more logical reason as why things happen the way they do
31.	and I give reason for everything and I have to give a reason for everything I do
32.	so there is always logic behind everything.
33.	
34.	I'm always positive and upbeat. I think it's also just, like, the way I was brought up
35.	and like you know that you think there could be worse things in life even like you guys,
36.	the doctors and seeing the other kids,
37.	there's always that hope that things are going to get better
38.	and it's like we are just kinda going down to our rock bottom and
39.	you kind of have to hit rock bottom before we can kinda of go up so…
40.	when you hit rock bottom, you can only go up
41.	

Page 1 of 6

1.	AND WHAT IS IT THAT MAKES YOU GO UP?
2.	Ummm... I think I have reason to live
3.	and there are so many who like support me and want me to get better
4.	and it's like I have to do this for them... I have to do this for them
5.	and I know I don't have to do it for them but I *want* to do it for them.
6.	
7.	So I want to be better for other people. Just...
8.	it's a fight and like you know a boxer in a ring, like a hockey player on ice,
9.	it's a fight to win and I am fighting to win.
10.	I'm not alone in this fight, definitely my grandparents and my mom.
11.	My grandma's like "Eat healthy, eat all these cancer fighting foods and go for walks", and all that,
12.	so and I'm going to try and change my diet and see if that helps. My mom is just always here.
13.	She cries more than me – I think. Like she is always asking why?
14.	Like, I don't know why I have cancer.
15.	I never really thought why me, I thought why not me because I probably…
16.	I have the energy to do this, I mean if it was me versus a 60 year old woman
17.	I probably have a better chance so, I say why not me.
18.	
19.	TELL ME ABOUT WHEN THIS FIRST HAPPENED TO YOU
20.	Ummm....that experience was a little, it's like a dream and they kept me pretty sedated, so it was pretty hazy through the whole thing.
21.	But I was just determined to kind of get out of VGH.
22.	I wanted to be high, (laughs) I mean … like having high spirits, just being in good spirits
23.	and I mean if you live with good spirits you have a good life,
24.	if you live with bad spirits you will live a bad life and you just want to live a happy life.
25.	Not because I believe in like a God per se but I definitely believe in a higher power
26.	'cause there are a lot of things in life that we can't control
27.	and I actually just had this discussion with my grandma.
28.	There are so many things in life that we don't control so something else has to be controlling it.
29.	
30.	DOES THAT HELP YOU?
31.	It helps a little bit because I think, you know I know we can't contact this higher power,
32.	some people believe they can as in speaking to God and you know
33.	and I think this higher power puts you in a place that you need to be,
34.	when you need to be there so I think I'm here for a reason, I'm just not sure what it is yet.
35.	Probably something to do with my wanting a psychology career.
36.	

1.	TELL ME ABOUT YOUR PSYCHOLOGY CAREER PLANS?
2.	I think because I have been put at a stand still right now.
3.	Like I had kind of had this plan for the future and I kind of would procrastinate and think
4.	"Oh maybe I'll wait a year and, you know, work for a bit and just have fun," and
5.	but I think now that I'm put at this bit of stand still where I kinda of have to put my life on hold to do treatment.
6.	I think it gives me more motivation to say "No wait, you wait for me to be done with my life first and then".
7.	I'm not going to just quit now that I'm sick. I've become super motivated.
8.	
9.	WHY?
10.	I'm not sure, I… sort, even at first I thought like
11.	"Oh my god, like I should be dead right now," or like you know....
12.	"Why like....why would I still be here... like why can't you just kill me now," or
13.	but I never even actually really thought that because it's like well,
14.	why did this happen and it was like what was the reason for this happening.
15.	And I think it's also the younger age, it's like we haven't lived life yet,
16.	we haven't experienced the world and it's like we want to get out and explore.
17.	You know like, I think maybe older people are like, "Well, I lived a good life, that's it." Like "I'm done."
18.	
19.	EXPLAIN MORE?
20.	I think seeing all these other kids helps me kind of sustain this motivation cause it's like...
21.	I just want to sit here and help everybody and it's like even just talking to them and
22.	even just at the Ronald Mc Donald House, you know there is a couple of kids who I see them
23.	like if they come back from radiation and they look like they are having a bit of a hard day or
24.	they look a little sore, give them a little bit of a hug like a gentle hug and just say
25.	just keep smiling and you can do this and you look great today and just kinda,
26.	I just wanna help people. So I think that, it really helps, it helps me to help others so, seeing others need help.
27.	Even as a little kid, I mean I always wanted to console other people when I was younger
28.	and I never wanted to, like, hurt anybody or do anything wrong and
29.	I just wanted to be friends with everybody.
30.	
31.	IS THERE ANYTHING ELSE THAT MOTIVATES THAT?
32.	I think a little bit comes from me, a little bit come from, now, the other kids.
33.	When I see other people overcoming obstacles and like, even cancer.
34.	I see these little kids overcoming cancer and I think that'll be me one day and one day it will be.
35.	To be honest, like I think my family help a lot.
36.	When they do all their research and when they say we have heard so many stories, like survival stories
37.	and so they give me all, you like know, this support for beating it and overcoming it.
38.	My mom has been through a lot and she can still be here for me, she keeps me positive,
39.	she's like my best friend…
40.	with cancer you find out who your real friends are through this for sure.
41.	

1.	MHMMM
2.	Aaahhh but the ones who have stuck around are definitely the ones that I will probably keep for life because they have been like really supportive.
3.	Sometimes like when I'm having a bad day and I don't want to talk to my mom,
4.	sometimes I'll have problems with my mom and sometimes I'll have problems with my dad
5.	and I don't want to talk to them so it's like you turn to a friend and say
6.	"Hey look I'm having this problem right now."
7.	and then they are completely supportive of get right back to you with that.
8.	
9.	TELL ME WHAT THESE PROBLEMS ARE?
10.	Arguments, teenager stuff, just stuff, but it's usually just I sit in my room,
11.	cry for an hour then I'm done or…I like music and …for a while it was just like writing…
12.	it was like a little bit of an escape so like a therapeutic kind of motion of some sort.
13.	
14.	WRITING WHAT?
15.	I used to write a lot of poetry and I'd write a lot of like happy…
16.	even when I was in this dark place I would write something happy.
17.	I'd write about my favourite things, I'd write about, you know, fall colours and how pretty they are and
18.	…cause…I actually have stopped writing now because, well a lot of the time I am tired and,
19.	you know, maybe when this is done I could write a book but right now
20.	I just wanna experience each day as it is and I don't wanna keep reflecting and…
21.	
22.	MHMMM
23.	I'm huge…into music. I just listen to a couple sad songs and then listen to my favourite song.
24.	And then I think "Oh, I can't help but sing along to this song."
25.	You know, you pick the songs that always make you feel like you wanna get up and dance every time you hear it?
26.	So my brother and I make playlists and when we jam out in the car
27.	those are the playlists that I'll play when I just need a pick me up and…
28.	I'm trying to learn Christmas carols on the piano, but…I'm not very good. (pause)
29.	
30.	TELL ME ABOUT AFTER CHRISTMAS PLANS?
31.	I have this weird belief where it's like, you know,
32.	once you're kinda finished with your purpose on Earth then you will die afterwards.
33.	So it's like you're here to fulfill your duty and then you pass away.
34.	And so I'm still here, I have to do my purpose.
35.	I'm here to help people and I think I'm here to help someone specifically.
36.	I'm not sure who yet, but I will find them along my travels, and they haven't been yet cause I'm still here.
37.	
38.	MHMMM
39.	At first it was finding my purpose and it's like now that I've kinda stumbled into this situation
40.	I think my purpose is to help people.
41.	And now that I think that that's my purpose or, I'm pretty sure, like ninety eight percent sure,
42.	I will fulfill my purpose until it is done and…
43.	

1.	WHERE DO YOU THINK THIS COMES FROM?
2.	Just the way my family brought me up, and I've had a…
3.	she's twenty-five now, a cousin…sort of, distant cousin who had multiple sclerosis
4.	and has been in a wheelchair her whole life and can't communicate, and so on so forth
5.	and just being around her has kinda taught my brother and I that, you know, there's a lot…
6.	you know, people are different and we need to just accept everybody just the way they are.
7.	
8.	CAN I GO BACK TO YOUR FRIENDS?
9.	Being able to talk to other people and just, you know, express how you're feeling…
10.	even if you're not expressing it directly. I mean you're always subtly expressing how you feel.
11.	Even in just like even the kind of tone or attitude you bring, you're expressing how you feel.
12.	And it's like other people can pick up on that. Some people can't, some people can and,
13.	you know, you kinda keep doing that until somebody picks up on it…
14.	
15.	So you need that, like, outside contact to kind of, you know, bring that out and make you express youself and…
16.	and you're like "Oh! A little bit of a weight has been lifted off my shoulders."
17.	I think my family has been more supportive…
18.	and then I've had, like, two or three friends that I just tell absolutely everything to.
19.	
20.	We text and because I live in (name of town) that's what…
21.	that's what makes me thankful for social media……
22.	Usually I'm kind of against it…and I've usually only used my phone for,
23.	for like calling my parents if I'm doing something, but…
24.	I think now I'm more attached to my phone than ever,
25.	'cause it's my contact to, like, all my friends and my family.
26.	
27.	WHAT IS THE WORST THING ABOUT THIS DIAGNOSIS FOR YOU?
28.	Just being plucked away from my home and put in Vancouver and…I just miss being at home.
29.	I've met a lot great kids here and a lot of cool doctors (giggles) and oncologists and just being, like,
30.	it, it gives you a whole new outlook on life and, like,
31.	my whole attitude has completely changed about, like, you know, even just being in hospital it's like…
32.	at VGH I, you know, wasn't in the Children's Hospital and I just wanted out of there and,
33.	I don't mind coming here every day for chemo and hanging out here and…seeing everybody.
34.	
35.	IF YOU COULD HELP ME HELP OTHER KIDS LIKE YOU WHAT WOULD IT BE?
36.	Well first it would be me getting my degree and coming back with more knowledge. (laugh).
37.	Umm, you can't really force somebody to find that hope or peace… but you can guide them.
38.	

1.	HOW?
2.	I think…it depends on the person, but I think my favourite form of showing people is through art.
3.	And like, you know, trying to find an artist in a kid.
4.	And it's like, you know, asking them to draw how they feel or ask them to draw a picture and
5.	it's like, you know, if they draw a sunshine and it's a big sunshine, it's like,
6.	you know that that child is full of sunshine and hope.
7.	But if they're starting to, you know…so I think…Any kind of form of art that comes naturally,
8.	because that's the way you express your feelings is through that art form.
9.	It's like if you can sense how they're feeling and kind of guide them to a more positive…
10.	I'm not quite sure how to do that yet, 'cause I need to take my therapy courses…Psychology courses.
11.	You know I want to be working either, like, in hospitals with children or at, like,
12.	have an office and have people come to me, and…kind of start off as, like,
13.	regular therapy kind of things, and then try new things and do different,
14.	no really experiments, but…I wanna help people with problems.
15.	
16.	MHMMM
17.	Like, any kind of problem, I just want to be able to help so, like, even if it's like, you know,
18.	marriage counseling I'd wanna help and, like…so any kind of counseling kids with cancer,
19.	kids with…prosthetics, kids with anything, I just wanna help anybody.
20.	
21.	SO WOULD YOU, WOULD YOU CALL YOURSELF A SPIRITUAL PERSON?
22.	Yes and no. I mean everybody has spirituality. Some people embrace it, some people don't.
23.	I just kinda go with it. Spirituality is just part of who are. It's just how you, how you are.
24.	It's like part of, part of your attitude, part of your behaviour, it has an influence on everything.
25.	Some people embrace their spirituality and really connect with it and…
26.	some people just say "Ehh…it's there".
27.	
28.	SO ARE THERE ANY QUESTIONS YOU HAVE ME?
29.	Mmm, nope. No. You're cool…I'm not one to inquire; I'm just one to go with the flow
30.	
31.	GOOD. THANK YOU SO MUCH

Field notes:

The interview took place in the clinic in the teen lounge. No interruptions and although she started in a very stilted way, she soon "opened up". She seemed very relaxed. It was a long interview; but even the talking seemed to give her purpose. She really wanted to talk.
She is my own patient so the slow start surprises me but her positivity surprises me as we've had many conversations around palliation.
Had some tears, especially talking of other little kids and her mom, but quick to turn to smiles.
After interview she shared some of her songs. (I think we could have gone on with interview)

Themes	Supporting texts (5BMS)
cancer/ diagnosis	2:14. 2:20. 2:21. 3:2. 3:7. 3:11. 3:12. 3:33. 3:34. 4:32. 5:11. 5:33
Hope/ meaning	1:37. 2:2. 2:9. 2:12. 2:22-24. 3:6.3:7. 3:14. 3:16. 3:34. 4:20. 4:32-36. 4:39-40. 5:6. 5:30. 6:6
positivity/future	1:24-26. 1:29-32. 1:34. 1:38-40. 2:15-17. 2:22-24. 2:35. 3:3-5. 3:20. 3:26. 3:36. 4:19. 4:25. 4:39-40. 5:31. 5:36. 5:37. 6:9. 6:11. 6:19
support	2:3. 2:5. 2:8. 2:10. 3:29. 3:35. 3:37. 3:38-39. 3:40. 4:2. 4:3-4. 4:5. 4:11. 5:6. 5:12. 5:16. 5:21-25
creativity	4:11-12. 4:15. 4:16. 4:23. 4:27. 6:2. 6:8
spirituality	2:25-28. 2:31-34. 3:17. 5:31. 5:37. 6:6. 6:22-24